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FOREWORD

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TABLE OF CONTENTS

Front Cover	1
Report Documentation Page (SF 298)	2
Foreword	3
Table of Contents	4
Introduction	5
Body	6
Key Research Accomplishments	10
Reportable Outcomes	10
Conclusions	11
References	none
Appendices	12

Introduction

Among African-American women younger than age 50, breast cancer incidence is almost twice that of Caucasian women. African-American women are more often diagnosed with aggressive tumors and have higher mortality rates than Caucasians. Differences in tumor biology and mortality do not appear to be due to factors related to socioeconomic status. Little is known regarding explanations for these racial disparities, perhaps because of the difficulty in enrolling African-Americans into research studies. The purpose of this pilot study was to develop a novel method of recruitment, focused primarily on minority women, and investigate previously unexplored risk factors in breast cancer epidemiology. Through rapid case ascertainment by tumor registries in Arkansas, we intend to enroll approximately 260 cases over two years, frequency-matched to controls randomly selected from Health Care Finance Administration (HCFA) and Arkansas Driver Services (ADS) lists. Cases and controls are matched to racially similar breast cancer survivorrecruiters. Potential participants are sent introductory postcards with the recruiters' photographs on them. Several days later, the recruiters call the potential participants to describe the study and seek their participation. Culturally appropriate interviewers administer questionnaires, draw blood and collect urine specimens from the participants. Once processed, data from these sources will be used to explore study hypotheses related to gene/environment interactions. We intend to evaluate the role that diet particular to African-Americans in the rural South may play in breast cancer etiology, and to assess the possible modification of risk by genetic differences in steroid hormone and carcinogen metabolism. A specimen bank was established to enable exploration of future hypotheses.

Body

The proposed work was a pilot case-control study of breast cancer in African-American women. We realized, however, that without a comparable Caucasian group from the same locales as the African-American women, interpretation of the data would be difficult. It would be impossible to determine if specific risk factors are more prevalent in African-American women and are, thus, related to the increased early age at onset and more aggressive disease, or if they are merely regional habits that are shared by women of both groups. Therefore, additional funding was sought from the Public Health Service Office of Women's Health (DHHS PHS OWH) to support an identical study in Caucasian women, so that results could be compared.

Research accomplishments associated with each Task outlined in the Statement of Work will be addressed within the context of each of the accomplishments.

<u>Technical Objective 1</u> Develop and pilot a novel approach for enrolling minority women into research studies.

Task 1: Months 1-2: Organizational start up tasks--finalize questionnaire, continue training sessions and role-playing with Witness ProjectTM recruiters and interviewers.

These tasks have been accomplished. The questionnaire is finalized (see appendix), interviewers are well-trained and experienced, and the recruiters are highly successful. Meetings are held regularly with recruiters to maintain enthusiasm and commitment, and to troubleshoot areas of difficulty. A paper detailing the recruitment strategies, 'Challenges, Limitations and Strategies for Increasing Participation in Epidemiologic Studies', has been submitted to Cancer Epidemiology, Biomarkers and Prevention' (6/99) as a Commentary (see appendix). In the spring of 1999, a presentation regarding recruitment methodology in our study was also presented at the National Action Plan on Breast Cancer Workshop on Multicultural Aspects of Breast Cancer Etiology in Washington D.C.

Task 2: Months 3-24. Identify incident breast cancer cases by rapid ascertainment; Identify controls from Department of Motor Vehicles and State Identity lists; recruitment of 230 cases and 230 controls by staff from Witness Project. TM Periodically assess effectiveness of individual recruiters by evaluation of response rates among women contacted by each individual.

Recruitment of both cases and controls is ongoing. The study has not moved as quickly as anticipated, primarily because of the inability to identify sufficient numbers of African-American women with breast cancer who are eligible for the study. Seventy-five percent of African-American Arkansan women who are diagnosed with breast cancer live in either Pulaski or Jefferson County. We currently identify cases through the Arkansas Cancer Research Center, the major cancer treatment facility in Pulaski County. A large

number of African-American women with breast cancer who reside in Southeastern Arkansas receive treatment at Jefferson Regional Medical Center (JRMC). While JRMC physicians agreed to allow us to contact their patients in December, 1996, access to tumor registry information was not forthcoming. Problems were first encountered with the JRMC Tumor Registrar, who was reluctant to release patient names. This situation was complicated by the fact that JRMC has no OPRR-approved Institutional Review Board. Thus, months were spent finalizing a Single Project Assurance with the OPRR and wrangling with legal concerns regarding access to patient names. All of these problems have been successfully overcome, however, and we are actively recruiting from JRMC. This still did not provide an adequate pool of eligible African-American women with breast cancer.

Two other approaches have been taken to identify additional African-American women with breast cancer. It appears that a significant number of women who live in Northeastern Arkansas in areas bordering the Mississippi River (the state boundary) seek treatment in Memphis, Tennessee, rather than travelling to central Arkansas. We are collaborating with physicians at the Methodist Healthcare Cancer Center (MHCC) in Memphis, Tennessee. They have agreed to allow us to contact women from Arkansas who seek breast cancer treatment at their Memphis facilities. Methodist Healthcare owns and operates 16 hospitals in West Tennessee and Central Mississippi and is the largest private, not-for-profit hospital in the country. It is also ranked number one in market share (38.3%) in Memphis according to the 1996 Joint Annual Reports of Hospitals. With hospitals in all four corners of Memphis, approximately 90 Arkansan women with breast cancer seek treatment at MHCC each year. We are also working with physicians in the Arkansas Department of Health Breast and Cervical Cancer Screening Program. The ADH Medical Director, Dr. David Bourne, refers women who are diagnosed with breast cancer through their screening program to our study.

Table 1 shows numbers of women enrolled into the study to date, and response rates for both African-American and Caucasian women. To date, interviews have been completed for 181 women, aged 29-75, with breast cancer and 48 community controls. The participation rate (the proportion of women who complete the study) for cases is 73% for Caucasian women, and 60% for African-American women. These rates are much improved over those using the standard methodology employed in an earlier study in this difficult-to-reach community, in which, for Caucasians and African-Americans (men and women) combined, participation rates were 37% and 30% for cases and controls, respectively.

As reported in the attached submitted manuscript, recruitment monitoring revealed that individual recruiter success rates varied considerably (65%-87% currently). The number of women contacted by each recruiter and response rates by recruiter are shown in Table 2. To capitalize on the most successful recruiters' experiences, we videotaped them recruiting potential participants by telephone to capture the unique methods employed to encourage participation. A wide range of successful tactics have been recorded and disseminated this way. These observations allowed us to rewrite the recruiters' script to incorporate elements found to be useful, and to reduce jargon.

We have also been actively recruiting controls, using the same methodology as we do for cases. The number of controls contacted to date is insufficient to report participation by race, but overall participation is excellent, at 89%. Table 3 shows progress for control ascertainment and recruitment. Due to unexpected programming difficulties with ADS and request processing difficulties with HCFA, control identification has been delayed. There are currently no obstacles preventing control identification or recruitment.

Task 3: Months 24-30

<u>Technical Objective 2</u> With a Food Frequency Questionnaire (FFQ) supplemented with foods commonly eaten by African-American women in the rural south, investigate the role of dietary sources of fat and heterocyclic amines in BC risk.

Task 1: Months 1-3 Adapt FFQ to include foods found to be commonly eaten by African-American women in Eastern Arkansas previously surveyed.

To determine if additional foods should be added to the Gladys Block Health Habits and History Questionnaire (HHHQ) to improve its suitability for African-American women in the lower Mississippi Delta, we conducted a survey of foods and cooking methods that may be particular to these residents. In collaboration with the Department of Dietetics and Nutrition at UAMS, a list of 60 foods commonly eaten by this population, such as wild game, parts of animals not traditionally eaten, and foods cooked with fat, was compiled through in-depth interviews and focus groups. We developed a Food Frequency Questionnaire with those foods elicited and then surveyed approximately 400 African-American women, aged 40 to 70, who live in eastern Arkansas. The survey indicated that few of the foods queried were eaten frequently by a large proportion of the population, but that several food items not on the Block questionnaire were eaten 1 to 4 times or more per month by > 50% of women surveyed. These foods included okra, southern peas (crowder, purple hull, split), butter and northern beans. Furthermore, more than 50% of women added fat when they cooked beans or greens, such as collards, mustard greens or kale. These additional items were added to the questionnaire already validated in Atlanta for a southern African-American population.

Task 2: Months 3-26 Interviews with cases and controls; ongoing monitoring of interviewers.

As stated above, interviewing of cases and controls is ongoing. Completed questionnaire booklets are reviewed weekly by the project director, Rebecca Morris-Chatta, MPH, for accuracy and coherence. Interviewer performance is thus evaluated continually. One phenomenon that we have observed using this methodology is the case in which a potential participant will agree when speaking with the recruiter, but then refuse when contacted by the interviewer. Late refusals may occur at the time the interview is scheduled, or after the interview is scheduled, often after several requests from the participant to reschedule. Interestingly, the pattern of late refusals varies by interviewer, and steps are being taken to train all interviewers in how to approach the potential participants who have already agreed to participate. We have also taken steps to cut down

on the amount of time between the recruiter contact and the interview scheduling. Late refusal rates have dropped 20% since these changes were implemented.

<u>Technical Objective 3</u> Evaluate genetic variability in metabolism of HAs by examining phenotypic variability in CYP1A2 and sulfotransferase activity, as well as genetic polymorphisms in *NAT1 NAT2*, *ST1A3* and *CYP1A2*.

Task 1: Months 3-26 Perform phenotyping assays for CYP1A2, NAT2, and phenol sulfotransferase

Task 2: Months 26-30 Perform DNA analysis for genetic polymorphisms in *CYP1A2, NAT1, NAT2, ST1A3*

We established a biologic specimen bank in the context of this study, and protocols for processing and storage of blood were developed. Blood samples are processed so that there are aliquots of serum, plasma, platelets, red blood cells, and buffy coat. Using a processing system currently used in the 350,000-person EPIC study in Europe, each blood component is mechanically aliquotted into several 0.5ml straws that are prestamped with an ID number and barcode. Straws are heat-sealed and stored in canisters in liquid nitrogen tanks, with a detailed computerized mapping scheme in place. Our laboratory routinely performs high throughput genotyping and has extensive experience in assaying all of the genes proposed for study.

In our ongoing efforts to validate the Risk-Tox Chip, a sample set of DNAs has been genotyped in our laboratory at ACRC. DNA samples with results for the NAT2*4 (wt), *5 $(T^{341}C)$, *6 $(G^{590}A)$, *7 $(G^{857}A)$ and the $COMT^H$ and $COMT^L$ using standard restriction fragment length polymorphism analysis were shipped to Genometrix Inc. Probe design for the microarray platform and primer design for multiplex PCR of NAT2 and COMT simultaneously have been developed at Genometrix. Our preliminary validation results of the "Prototype Risk-Tox Chip" using this sample set showed excellent concordance between the two methods. We expect that within the next six months, the chip will be completed, with all genes of interest validated. At completion of data collection, we will be able to quickly and efficiently perform genotyping assays.

Task 3: Months 31-36

Key Research Accomplishments

- Establishment of infrastructure for molecular epidemiologic study (questionnaire development, protocols and equipment for blood processing and specimen banking, recruiter and interviewer hiring and training, development of data bases for participant tracking and questionnaire data, etc.).
- Enrollment of cases and controls into study response rates far superior to those in earlier case-control study in the same locales.
- Adaptation of FFQ to the African-American population in Arkansas.

Reportable Outcomes

Presentation at National Action Plan on Breast Cancer Workshop on Multicultural Aspects of Breast Cancer Etiology. Washington DC, 1999. Erwin DO, Morris-Chatta R, Long S, Ambrosone CB. An innovative method for increasing participation of African-American women in epidemiological studies.

Manuscript on recruitment submitted to Cancer Epidemiology, Biomarkers and Prevention - Erwin DO, Morris-Chatta R, Long S, Ambrosone CB. Challenges, Limitations and Strategies for Increasing Participation in Epidemiologic Studies.

Biologic specimen bank established with DNA, serum, plasma and red blood cells from cases and controls.

Grant submitted to NCI 2/99, 'Breast Cancer in the Lower Mississippi Delta'. Investigators: Ambrosone, Fontham, Erwin, et al.

Conclusions

In this pilot study, case ascertainment has been accomplished through collaborations with physicians at the Arkansas Cancer Research Center (ACRC) in Little Rock; Jefferson Regional Medical Center (JRMC) in Pine Bluff, Arkansas; Methodist Healthcare Cancer Center (MHCC) in Memphis, Tennessee and through the Arkansas State Department of Health. Controls have been identified through the Health Care Finance Administration and Arkansas Driver Services enrollment files. Interviews have been conducted using a questionnaire adapted from one developed by John Potter and Kristen Anderson at University of Minnesota, and used in a study of colorectal cancer in Arkansas (Lang, PI). This instrument was modified to collect data on breast cancer risk factors using the validated questionnaires from the Western New York Diet Study and the Women's Health Initiative. Blood and urine samples for genotyping and phenotyping have also been obtained. We have established a biologic specimen bank, with a detailed protocol for blood processing and storage. All of the assays to be performed have been refined in our laboratories at the ACRC and National Center for Toxicological Research (NCTR). Recruitment is well underway and the methodology appears to be a vast improvement over previous work in this area.

Full-scale epidemiologic studies require large budgets, which include personnel, supplies, equipment, etc. Furthermore, building of an infrastructure is essential, yet laborious and time-intensive. There was little to no organized epidemiologic studies being conducted in Arkansas when this study was initiated, and funding received from the Department of Defense and the OWH has been used to develop the infrastructure and get it the study into the field. We now have cooperation from several major hospitals in the Mississippi Delta and the Arkansas Department of Health, and expect to more quickly ascertain African-American women diagnosed with breast cancer in the coming year. Our methodology has been established and tested, staff training manuals have been developed (see appendix) and successfully piloted, and a specimen bank has been established and is in use.

DOD Annual Report Tables

Table I
Study Enrollment - Cases

Race	Enrolled	Refused	Participation %	TOTAL
African-American	31	21	60	52
Caucasian	146	53	73	199
Other	4	0	100	4
TOTAL	181	74	71	255

Table II

Recruitment by Recruiter

Recruiter	Agreed	Refused	Recruitment %	Late Refusers	TOTAL ATTEMPTS
1	125	21	87	18	164
2	76	14	86	8	98
3	15	8	68	2	25
4	4	0	100	0	4
5	9	6	65	2	17
6	0	1	0	0	1
TOTAL	227	50	82	30	309

Table III Study Enrollment – Controls

Race	Enrolled	Refused	Participation %	TOTAL
African-American	1	2	33	3
Caucasian	47	4	92	51
Other	0	0	0	0
TOTAL	48	6	89	54

Appendices: Submitted manuscript Presentation abstract Questionnaire Adapted HHQ Training manual

Challenges, Limitations and Strategies for Increasing Participation in Epidemiologic Studies

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Participation in epidemiologic studies

Abstract

Low participation or differential participation rates for cases and controls in epidemiologic studies is a growing problem in research. Selection bias could be responsible for findings that are not generalizable to the general public, and also for inaccurate risk estimates between exposures and disease outcomes. It is especially important in many studies to adequately recruit minority participants. This report describes the potential utility of an innovative method for increasing participation through the help of patient advocates. The barriers and challenges to study accrual and the theoretical foundation for utilization of patient advocates are discussed. The research experience in breast and prostate cancer is used as a model for developing interventions to explore improved methods for recruitment of cases and controls. A model incorporating community-based, ethnically-matched male and female cancer survivors and culturally competent interviewers is recommended.

Introduction

In support of the need for research findings that can be generalizable to all individuals within a heterogeneous population, the 1993 NIH Revitalization Act requires minority groups to be included as subjects in clinical research. Difficulty in recruiting individuals into research studies appears to be a growing universal trend, but is particularly significant in special populations. This report describes the barriers and challenges to study accrual, with a focus on minority populations. It also discusses an innovative method for increasing participation through the help of patient advocates.

Non-participation and selection bias

Participation by all possible individuals who are eligible for enrollment in epidemiologic studies is critical. Low participation or differential participation rates for cases and controls could result in selection bias. This bias will be strongest if the relationship between the exposure and disease observed among those who participate in the study is different from the exposure/disease relationship for individuals who would have been eligible but were unwilling to participate. Those who agree to participate, particularly in a study that requires an extensive interview and blood specimen collection, may be more interested in health matters than those who decline to participate. These participants may be less apt to smoke cigarettes or drink excessive alcohol, or more likely to eat a healthier diet, exercise regularly, and maintain ideal body weight.

For example, in a molecular epidemiologic study of breast cancer in Western New York (1), only a subset of study participants agreed to provide a blood specimen. Comparison of those who consented to phlebotomy to those who refused revealed that, while there

was little difference between cases, controls differed on a number of potential breast cancer risk factors. Controls who agreed to give a blood specimen had significantly fewer pregnancies, were less likely to smoke, and were higher consumers of chicken and fish and lower consumers of beef than those who refused. This resulted in skewed estimates of risk. While overall no association existed between breast cancer risk and cigarette smoking, smoking increased risk among the subset of women who gave blood. In the larger data set, there were equal proportions of 'never smokers' in the referent category for cases and controls, while among those who provided a specimen, there were twice as many controls who had never smoked as cases.

When differences between participants and non-participants can be evaluated in a study such as the example given above, this bias can be taken into account in the analytic approach. However, when there is not extensive data on those who refuse, the likelihood and extent of selection bias is difficult to ascertain. Clearly, for valid case-control study results, the maximum number of eligible individuals should be enrolled.

Reasons for non-participation

Much of the groundwork for the study of barriers to participation and generation of strategies to increase participation in biomedical studies has been laid in the field of clinical trials. Ness and colleagues (2) reviewed the literature in 1997 and concluded that "the published literature currently contains insubstantial data to either refute or prove that there are differential recruitment rates among minorities as compared with whites" in clinical studies. This review of published literature between 1993 and 1995, however,

reflected research generally accomplished several years prior to the 1993 Revitalization Act in which NIH stated that minority groups must be included as subjects in clinical research; thus, reporting of recruitment difficulties may not have been relevant.

Other national data in this genre suggest that minorities may be underrepresented in clinical trials (3-5). Lack of participation and accrual has been attributed to a variety of barriers. These include: treatment cost problems due to low socioeconomic status, lack of bilingual or culturally sensitive staff, perceived efficacy of investigational programs or trials, lack of protocol availability for minorities related to lower eligibility/later diagnosis, lack of community involvement and support, and difficulties related to poverty, such as hopelessness, powerlessness, and survival priorities (2; 5-12).

Some of these barriers may be specific to a particular ethnic group or gender, others are more closely related to poverty. In a comprehensive review of the literature on recruitment for controlled clinical trials, Lovato (4) and colleagues list "lack of trust" as one of the most common barriers to participation. Those sub-populations unfamiliar with the nature of research studies or those who are wary of the medical community may be most difficult to recruit. For example, the recruitment of African-Americans into research studies is historically difficult (5), perhaps because of the extensive knowledge among African Americans of the Tuskegee Syphilis Experiment. That breach of ethics in a research study may have created a sense of "distrust and suspicion that hampers cancer research efforts in many Black American communities" (13)(14). Because barriers to

recruitment may vary among age and race subgroups, recruitment strategies need to be tailored to specific potential participants (15)(16).

Enhancing recruitment to clinical trials

The recruitment of minority participants to research studies often requires more time and money than accrual of Caucasians (16), with the use of additional targeting strategies. In light of the intensity of the time and effort required, El- Sadr and Capps (3) have even suggested that the definition of research costs should be broadened to include the funding of meals, social and outreach services, transportation, child care, and educational materials to enhance the success of minority recruitment. Moreover, they stress the importance of a "realistic estimation of the number and types of personnel needed to successfully recruit, retain, and follow" trial participants.

To reduce the suspicion and distrust that may discourage participation in research studies, some studies indicate that attention be given to characteristics of the investigators. In a review of the literature, Kelly and Cordell (17) report that the recruitment and retention of women is significantly improved (enrolled at twice the rate) in studies in which some or all of the principal investigators are female as compared to studies in which all of the investigators were male. While gender of the investigator has been shown to be important, cultural background may be even more so. Interestingly, although interviewer effects have been considered less important in telephone surveys, Moorman and colleagues (15) found in the North Carolina Breast Study that results of even the first contact by phone were dependent on or influenced by the perceived race of the interviewer. While cooperation rates were highest among both black and non-black

women when interviewers and participants were concordant on race in this study, cooperation rates were lowest among controls, older women, and African American women with breast cancer in comparison to Caucasian women.

These examples demonstrate the inadvertent gender and ethnic messages and barriers that may exist without advocates and diversity present in the staff personnel. Qualified bilingual/bicultural staff provide important cultural liaisons to the clinical population as well as to the institution in the development of protocols and study designs (18)(19). Studies indicate that nonjudgmental, supportive staff, drawn from the same community as the desired population, establishes trust more easily (17). For African-Americans, the use of African-American interviewers may be reassuring and better demonstrate that the research is important and relevant to people of their community, thus increasing the likelihood of overcoming a mistrust of medical researchers (15)(3). The ability of the nine Minority-Based Clinical Community Oncology Programs (MB-CCOP) to accrue 10% of all minority participants to NCI-sponsored oncology trials further supports the importance of cultural competency in the staff (20).

In a review of the literature, Swanson and Ward (5) conclude that the most effective method of recruitment is from the community rather than the health care system.

Likewise, Lovato et al. (4) listed successful recruitment strategies in minority populations as those programs which honor important cultural values (10) and utilize community leaders and relationships with community gatekeepers, including one-to-one

communication strategies (21; 22). The Women's Health Trial Feasibility Study in Minority Populations was successful in recruiting minority women to a nutritional intervention study, including participants with low literacy skills. This was accomplished through a thorough, intensive, focused recruitment campaign including mass mailings, the media, referrals, and community outreach by a dedicated culturally competent staff (16; 23). Many of these principles have been applied to programs throughout the United States, including our own programs in Arkansas, described below.

Because meaningful epidemiological cancer research cannot be performed in human populations without maximal participation, and because recruitment is often low in African-American and other minority communities, developing effective new recruitment methods for difficult-to-reach populations is critical. Building upon a strategy in which African-American women who were breast and cervical cancer survivors were recruited, trained, and promoted as role models and lay health advisors (Witness Project®) in the medically-underserved Mississippi Delta region, we describe a methodology developed for recruitment of participants, particularly minorities, into epidemiologic studies.

Developing the model- education and outreach

Low income and low literacy populations have not been adequately reached with traditional health communication strategies designed for the general public. The theoretical basis for our outreach recruitment project included communication strategies and models for behavior change that address many of the same barriers that apply to clinical trial accrual. To be effective, messages must meet the needs of individuals at all literacy levels and cultural

backgrounds. For individuals who read poorly, the setting needs to be peer-oriented and focused on perceiving information concretely, and on processing information actively (24). Messages must regard all styles of learning and both brain hemisphere preferences. Both achievement and attitude are affected positively when learning styles and left and right brain preferences are addressed (25). Many individuals without formal educational backgrounds are right-brained processors who learn best from demonstrated instructions in an open-ended setting that includes emotional judgements (26). Cancer survivors can provide these experiential, right-brain, personal messages.

Important predictors of behavior are related to cognitive and sociocultural models such as health beliefs (27), health locus of control (28), social relationships (29), and social norms (30). In cancer screening and education, projects that use direct education (in-person, small groups, one-on-one or tailored messages) with culturally sensitive methods are the most effective cues to action for addressing health beliefs (31-34). Direct education methods by survivors to patients, as peers from similar cultural backgrounds, will provide a meaningful message that can help patients address and overcome the emotional, social, and experiential issues and barriers involved in participation in research studies.

With respect to minorities, recent information about outreach programs and the knowledge gap between Caucasians and African Americans indicates a credibility problem related to the transfer of information to underserved populations. Freimuth reports that in the African-American population, there is a "preference for ordinary African-American people who had

experienced and overcome a problem," (35) to be the messengers, which is the basis of the Witness Project® model.

The Witness Project® was developed to increase awareness of breast and cervical cancer and to encourage screening for early detection in rural African-American communities. In this program, African-American women who are breast and cervical cancer survivors are recruited, trained, and promoted as role models and lay health advisors. These women speak at rural churches and in community settings about the need for breast self-examination, clinical breast exams, screening mammography, and Pap tests (36). The Witness Project® volunteers report that often a diagnosis of breast cancer is veiled in shame and secrecy in rural African-American communities. Cancer is feared and dreaded, and there is little open discussion about treatment, causes, or the personal experiences related to a breast cancer diagnosis. Results from the Witness Project® indicate that this program is an effective method to reach and communicate with minority women. Furthermore, post-intervention surveys of participants demonstrate a significant increase in the practice of breast self-examination and mammography as compared to women in the control group (36; 37).

Although the Witness Project® was designed for reaching rural African-American women for the purpose of increasing early detection, this role model method may be effective for recruitment of women to epidemiological studies. This type of initiative, involving women from various cultural backgrounds to speak to potential study participants, is likely to address the social and cultural issues of credibility, trust, empowerment, perceived efficacy, language, and community support. Survivors as role models and messengers are often better

able to educate and inform their peers in a culturally appropriate way. One of the key factors may be the fact that these role models are able to relate to their audience on a personal level because they share spiritual and cultural lifestyles and beliefs that increase the level of trust in the relationship (37). This is equally true for the study recruitment of men as well as women.

The Witness Project® model was expanded to the *Patient Advocates for Clinical Trials* (*PACT*) project. This *PACT* project was a two-year study designed to investigate the feasibility of overcoming sociocultural barriers to participation in clinical trials through systematic use of breast cancer survivors serving as role models to inform other women about clinical trials. Nineteen women who had participated in a breast cancer clinical trial were trained as *PACT* advisors and matched by ethnicity, income, education, age, and geographic region of the state (urban/rural) to talk with 35 new breast cancer patients. Full results of this study methodology and research results will be reported in another paper, but current results indicate that survivors are enthusiastic about serving as part of a "recruitment team" and 55.5% of the new patients deemed clinically eligible for trials were subsequently enrolled after talking with a *PACT* advisor.

Cancer survivors as recruiters to epidemiologic studies

The Mississippi River Delta is a region of high minority and low income populations, and residents are often wary and distrustful of the medical community. In an earlier case-control study of cancer in central and eastern Arkansas, recruitment of subjects into the study was extremely difficult and participation rates were low. Potential participants were

contacted by telephone, and response rates were approximately 30% for controls, and 37% for cases. Utilizing models developed in the *Witness Project* and the *PACT* project, we developed an innovative method of recruitment that has been more successful than the one used in the earlier case-control study. First applied to an epidemiologic study of breast cancer, this approach is also being used in a case-control study of prostate cancer.

Women who were breast cancer survivors and were volunteers for the *Witness* and *PACT* programs, and later, men who were prostate cancer survivors, played an integral role in development of strategies for recruitment for our epidemiologic studies on breast and prostate cancer, developing the following methodology. Women and men who are breast or prostate cancer survivors are trained in our recruitment approach. They are matched to potential participants (cases and controls) by race and area of residence. This provides a culturally-appropriate process for overcoming many of the barriers to recruitment, especially for African-American men and women. Relying on data obtained from focus groups and interviews, training procedures have been standardized in a training manual. During training sessions, recruiters participate in role-playing in order to consider the numerous possible reactions potential participants may have when contacted and to learn how to respond to each. By the end of training, recruiters understand the importance of having good response rates for valid results.

After a case or control has been notified that they may be contacted and that their physician is aware of the study (for cases only), they are matched with a culturally appropriate recruiter from the same residential area. An introductory postcard with a

photograph (Figure 1) of the recruiter (devised as a result of recruiter feedback) is mailed to the potential participant, explaining that the recruiter is a breast/prostate cancer survivor, that she/he lives nearby, and will be calling soon to discuss the research study. Several days later, the recruiter calls the potential participant, describes study goals and discusses the interview procedure, following a basic script that has been tested in focus groups, and role-played with the breast and prostate study recruiters.

Because older women often have higher refusal rates, specific fears and concerns may need to be addressed. For example, in our experience, and as described for a case-control study in North Carolina (15), older women are often fearful of having strangers come into their home for an interview and may want to meet at another location, usually their doctor's office or local eating establishment. Talking with a family member may help to confirm the legitimacy of the study, and having someone else present for an interview may make the study more acceptable (15). It is also useful to have professionally produced brochures that describe the study, show the study staff, and answer questions commonly asked regarding the study to send to the potential participants.

Recruiters are paid \$10 for successful contacts, and \$5 for those who refuse. If the individual agrees to participate, an interviewer of the same race schedules an interview, either at the participant's home or at another convenient location. Focus groups determined that it was important for women only to be interviewers for the breast cancer study. However, prostate cancer survivors felt that a female interviewer would be acceptable for men. The recruitment process often serves as a source of support and

networking for women newly diagnosed with breast cancer. Participants in the study are offered a \$25 gift certificate to one of several local and national retailers. Many people in the Delta live in extreme poverty, and in our experience, this small remuneration not only increases incentive to participate, but is also greatly appreciated.

To date, interviews have been completed for 215 women, aged 29-75, with breast cancer; enrollment of community controls is in the active recruitment phase. Participation rates (the proportion of women who complete the study) for cases are 80% for Caucasian women, and 72% for African-American women. While the prostate study is in the very early stages of enrollment, 76% of the men contacted have agreed to participate. These rates are much improved over those using the standard methodology employed in an earlier study in this difficult-to-reach community, in which participation rates were 37% and 30% for cases and controls, respectively for Caucasians and African-Americans (men and women) combined.

Recruitment monitoring revealed that individual recruiter success rates varied considerably (67%-88%). To capitalize on the most successful recruiters' experiences, we used videotaped recruitment telephone calls to capture the unique methods employed by recruiters to encourage participation. A wide range of successful tactics have been recorded and disseminated. These observations allowed us to rewrite the recruiters' script to incorporate elements found to be useful, and to reduce jargon. Concise, friendly conversations by recruiters who are confident and proficient with study information are the most successful.

To maintain enthusiasm and motivation of the staff, recruiters are paired with an interviewer 'buddy' who contacts them weekly. These staff members build rapport, provide a venue for open communication, and encourage feedback. This feedback is often implemented in study methodology improvements. The recruiters have a unique perspective on the recruitment process, as cancer survivors and key informants. Quarterly 'barbecues' are held as opportunities to meet on a social and professional level. The quarterly meetings may include discussion of necessary changes in the protocol, sharing success stories, and watching videotaped participant contacts of each recruiter. Recruiter satisfaction has increased as a result of additional focus on the recruitment role, reducing turnover. Experience appears to play a large role in recruitment success; it is hoped that increased satisfaction will lead to long tenure in the recruiter role.

One phenomenon that we have observed using this methodology is the case in which a potential participant will agree when speaking with the recruiter, but then refuse when contacted by the interviewer. Late refusals may occur at the time the interview is scheduled, or after the interview is scheduled, often after several requests from the participant to reschedule. Interestingly, the pattern of late refusals varies by interviewer, and steps are being taken to train all interviewers in how to approach the potential participants who have already agreed to participate. We have also taken steps to reduce the amount of time between the recruiter contact and the interview scheduling.

Potential participants who are women and men with cancer clearly appreciate the shared breast and prostate cancer experience and comment regularly that they are pleased to

speak with another woman or man who understands what they have been through.

Recruiters and interviewers are regularly thanked by the participants for their efforts.

Some participants have been so positively impacted by their recruitment experience that they have written thank-you notes, asked to be re-contacted by the recruiter, and have baked cookies for the interviewer. There have been no intensely negative responses in hundreds of participant interactions.

In addition to attention to sociocultural issues, an appropriate data management system designed to allow rapid, objective monitoring of recruitment performance regularly at staff meetings provides process evaluation to improve recruitment (16; 17; 19). Although further evaluation of this method is planned, these preliminary process evaluations indicate that this is a promising strategy for optimizing the recruitment of epidemiological study participants. In addition, it is an important collaborative step in increasing the role and contribution of survivors and advocates into the research design process.

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Figure Legend

Figure 1. Postcard sent to potential 'control' participant, matched with recruiter by age, race, and county of residence.

· Hi,

My name is

I am a breast cancer survivor and do patient education and outreach at the University of Arkansas for Medical Sciences and Jefferson Regional Medical Center.

Your name was randomly picked from the Driver's License Bureau and I am going to call you soon to tell you about a study we are conducting at UAMS.



AN INNOVATIVE METHOD FOR INCREASING RECRUITMENT OF AFRICAN AMERICAN WOMEN TO EPIDEMIOLOGICAL STUDIES, Deborah O. Erwin, , Rebecca Morris-Chatta, Stephanie Long, Christine Ambrosone; Arkansas Cancer Research Center at the University of Arkansas for Medical Sciences

OBJECTIVE: Low participation in epidemiologic studies is a significant problem.

Those who do consent may not be representative of the general population. The development and refinement of methodology to effectively encourage African-American participation in research studies is the objective of this presentation.

METHODOLOGY: Utilizing models developed by the authors for cancer education outreach in *The Witness Project*® and treatment trial recruitment in the *Patient Advocates for Clinical Trials (PACT)* project (RO3, NCI), we developed an innovative method of recruitment that has been more successful than those used previously at our institution. Women who are breast cancer survivors are matched by racial and residential backgrounds to the potential participants to contact cases and controls for this study. This provides a culturally-appropriate process overcoming the barriers to recruitment, especially for African American women. Relying on data obtained from focus groups and interviews, training procedures have been standardized in a training manual.

RESULTS: To date, 20 of the 29 (69%) African-American women contacted for the breast cancer study have agreed to participate, as have 106 of the 146 (73%) Caucasian women.

CONCLUSION: These rates are not optimal, but they are much improved over those using standard methodology in this difficult-to-reach community (30% of controls, and 37% for cases). Some recruiters are more successful than others, therefore, we have videotaped all of the recruiters making telephone calls for both the breast cancer pilot study. The successful interactions are, in general, brief, friendly, and informative. As a result of these observations, the recruiters' script has been re-written to incorporate elements found to be useful and to reduce jargon.

Health Habital Questionnaire



Carcinogenesis Unit of the Division of Surgical Oncology



UAMS MEDICAL CENTER

Strong Medicine for Arkansas

Research Study Number One

Interviewer, please enter the date of diagnosis in the following format: MMDDYY, e.g. April 4, 1950 equals "040450"

RFDT

1

M = M = D = D = Y = Y

Since many people have never been in an interview exactly like this, let me start by reading you a paragraph that tells a bit about how it works. I am going to read you a set of questions exactly as they are worded so that every respondent in the study is answering the same questions. You'll be asked to answer two kinds questions. In some cases, you'll be asked to answer in your own words. For those questions, I will have to write down your answer word for word. In other cases, you will be given a list of answers and asked to choose the one that best fits. If at any time during the interview you are not clear about what is wanted, be sure to ask me. Also, it is very important that your answers be accurate and complete. Please take as much time as you need.

I'd like to begin by asking you some questions about your background. What is your date of birth?

A001

(Enter in MMDDYY format)

 $\overline{\mathbf{M}} \ \overline{\mathbf{M}} \ \overline{\mathbf{D}} \ \overline{\mathbf{D}} \ \overline{\mathbf{Y}} \ \overline{\mathbf{Y}}$

Interviewer, please enter the date of birth again for accuracy check.

AO1b

(Enter in MMDDYY format)

 $\overline{\mathbf{M}} \ \overline{\mathbf{M}} \ \overline{\mathbf{D}} \ \overline{\mathbf{D}} \ \overline{\mathbf{Y}} \ \overline{\mathbf{Y}}$

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What is the highest grade or year of A002 school or college that you have completed? 1 Eighth grade or less 2 Trade school or business school instead of high school 3 Some high school 4 High school graduate or G.E.D. 5 Trade school or business school after graduating from high school 6 Some college including 2 year degrees Received bachelor's degree 8 Graduate or professional education beyond the bachelor degree Graduate or professional degree 98 F DK 99 [R Please look at this card and tell me which choice best describes AOO3 your race? (Interviewer: show respondent card A) African-American 2 White, not of Hispanic origin 3 Hispanic Asian or Pacific Islander Native American or Alaskan Nativ Other [specific] 98 □ DK 99 ∏ R Are you currently married, living as married, A004 widowed, divorced, separated, or never married? Married 2 Living as married Widowed 4 Divorced Separated 5 F Never married 98 <u>[</u> DK 99 [R

Breast Cancer Risk Study; ver4. January 21, 1999

SMOKING HISTORY

Have you ever smoked at least one		SH1
cigarette per day for one year?		
(CHECK ANSWER)		
	1 Yes	
	2 No (go to HTX)	
	98 🔲 DK (go to HTX)	
	99 R (go to HTX)	
In what year did you first (next) start smoking cigarettes?		SH2
	(write year)	
N:1		SH3
Did you ever stop smoking cigarettes for six consecutive months or longer?	•	5113
for six consecutive months of longer:		
	1 TYes	
	2 No (go to SH5)	
	98 DK (go to SH5)	
	99 \(\text{R} \) (go to SH5)	
If you what your did you ston?		SH4
If yes, what year did you stop?		
	(write year)	
During the time that you smoked, how m did you usually smoke in a day?	any cigarettes	SH5
# ciga	rettes	
•••	98	
	99 🔲 R	
		CU6
What year did you start smoking next?		SH6
	(write year)	

Breast Cancer Risk Study; ver4. January 21, 1	1999	. ' . ' 4
Did you ever stop smoking cigarette for six consecutive months or longer		SH7
	2 No (go to SH9) 98 DK (go to SH9) 99 R (go to SH9)	
What year did you stop smoking?		SH8
	(write year)	
How many cigarettes per day did you smoke?		SH9
;	# cigarettes 98	
Were the cigarettes you smoked, filtered?		SH10
	1	
	1 Not at all 2 Mouth or throat 3 Chest 98 DK 99 R	SH11

_	
5	
J	

. Breast Cancer Risk Study; ver4. January 21, 1999

Did you start smoking again?	1 Yes 2 No 98 DK 99 R	SH12
What year did you start smoking	next?	SH13
	(write year)	
Did you ever stop smoking cigare for six consecutive months or lon		SH14
	1 Yes 2 No (go to SH16) 98 DK (go to SH16) 99 R (go to SH16)	
What year did you stop smoking	?	SH15
	(write year)	·
How many cigarettes per day did you smoke?		SH16
	# cigarettes 98	
Were the cigarettes you smoked, filtered?	1 Filtered	SH17
	1	

Breast Cancer Risk Study; ver4. January 21, 1999	
How did you inhale? 1 Not at all 2 Mouth or throat 3 Chest 98 DK 99 R	SH18
Did you start smoking again? 1 Yes 2 No 98 DK 99 R	SH19
What year did you start smoking next?	SH20
(write year)	
Did you ever stop smoking cigarettes for six consecutive months or longer?	SH21
1 Yes 2 No (go to SH23) 98 DK (go to SH23) 99 R (go to SH23)	
What year did you stop smoking?	SH22
(write year)	
How many cigarettes per day did you smoke?	SH23
# cigarettes 98	

•

Were the cigarettes you smoked, filtered?		SH24
	1 ☐ Filtered 2 ☐ Non-Filtered	
	2 Non-Filtered 3 Both	
	- 98	
	99 🔲 R	
How did you inhale?		SH25
110W did you innaio.	1 Not at all	
	2 Mouth or throat 3 Chest	
	98 DK	
	99 🔲 R	
Did start amaking again?		SH26
Did you start smoking again?	1 Yes	5H20
	2 No	
	98	
What year did you start smoking	neyt?	SH27
What year did you start smoking	MVAV.	
	(write year)	
Did you ever stop smoking cigaret	ites	SH28
for six consecutive months or long	ger?	
	1 Tyes	
	2 No (go to SH30)	
	98 DK (go to SH30) 99 R (go to SH30)	
	(80 00 00 00 00)	
		GYYZO
What year did you stop smoking?	<i>!</i>	SH29
	(write year)	

OCCUPATIONAL HISTORY

INTRODUCTION: Now I'd like to ask you some questions about the kind of work you have done. We are interested in every job, at home, or outside the home, part-time or full-time, paid or unpaid, including any self-employment, or work for companies or family businesses, which you held for a total of six continuous months or longer since you first began working. If you held more than one job at a company, or more than one job at the same time, we would like to talk about each job separately. Also, please include any time while in the military. If you get tired during this section, we can stop and resume at another time. Let's begin by listing only the employer name, job title, and years worked at each job.

Are you currently employed, not employed, (a home maker), or retired? (DO NOT ASK HOME MAKER IF SUBJECT IS MALE.) 1 Employed 2 Unemployed 3 Retired 4 Home maker	ОН1
A. In what year did you start being a home maker? (write year)	OH2
B. Did you ever have any jobs outside the home? 1 Yes 2 No 98 DK P. 29, OC3 99 R	ОН3

What was the name, city, state and of the company where you (first/n worked for six months or longer?	ext)		OH4 Text No code
(IF MORE THAN 4 JOBS, USE CONTINUATION SHEETS)			
	NAME:		
	City,	State,	County
What was the job title of the (first you held for six months or longer			ОН5
	. (JOB	TITLE/ COMPANY)	
In what year did you start workin (JOB TITLE) at (COMPANY)?	g as		ОН6
	(write year)		
In what year did you stop working as a (JOB TITLE)?	3		ОН7
GO TO NEXT JOB. WHEN YOU HAVE OBTAINED FOR FIRST JOB, GO TO OH20.			
·	(wri	te year)	

What was the name, city and count of the company where you (first/neworked for six months or longer?	ext)		OH8 No Code
	NAME:		
	City,	State,	County
What was the job title of the (first/you held for six months or longer	next) job at (COMPANY)?		ОН9
	(JO	B TITLE/COMPANY)	
In what year did you start workin (JOB TITLE) at (COMPANY)?	g as		OH10
	(write year	r)	
In what year did you stop working as a (JOB TITLE)? GO TO NEXT JOB.	g		OH11
WHEN YOU HAVE OBTAINED FOR SECOND JOB, GO TO OH			
	(write year)	

What was the name, city and county of the company where you (first/next) worked for six months or longer?			OH12
(IF MORE THAN 4 JOBS, USE CONTINUATION SHEETS)			
NAI	ME:		
City	у,	State,	County
What was the job title of the (first/next) you held for six months or longer at (C			ОН13
• ,	(JOI	B TITLE/COMPANY)	
In what year did you start working as (JOB TITLE) at (COMPANY)?			OH14
	(write year)	_	
In what year did you stop working as a (JOB TITLE)?			OH15
GO TO NEXT JOB. WHEN YOU HAVE OBTAINED OH! FOR THIRD JOB, GO TO OH28.	12-OH15		
	(write	e year)	

What was the name, city and coun of the company where you (first/ne worked for six months or longer?			OH16
(IF MORE THAN 4 JOBS, USE CONTINUATION SHEETS)			
	NAME:	·	·
	City,	State,	County
What was the job title of the (first/ you held for six months or longer :	next) job at (COMPANY))?	OH17
		(JOB TITLE/COM	PANY)
In what year did you start working (JOB TITLE) at (COMPANY)?	g as		OH18
	(writ	e year)	
In what year did you stop working as a (JOB TITLE)?	5	·	ОН19
GO TO NEXT JOB. WHEN YOU HAVE OBTAINED FOR FOURTH JOBS, GO TO OI			
		(write year)	

01 = Manufacturer 02 = Retailer	
03 = Wholesaler	
04 = Service Provider 05 = Construction	
06 = Mining	
07 = Farming/Fishing/	
Forestry 08 = Government	
09 = Other Specify (in table)	
10 = Shipyard	
You said you worked as a (OH5) from (OH6)	OH20
to (OH7) at (OH4). What type of business was (OH4)? Was it a (READ KEY)?	· ·
Code	
(industry)	
Other	
Other(specify)	
What did (COMPANY) make,	OH21
or what service did they provide?	OHZI
(Industry description/Same as OH20)	
What were your main activities or	OH22
duties as a (JOB TITLE) at (COMPANY)?	
(Duties)	

Breast Cancer Risk Study; ver4. January 21, 1999	1
What kinds of chemicals or materials did you handle in that job?	ОН23
(Chemical/Materials)	
You said you worked as a (OH9) from (OH10) to (OH11) at (OH8). What type of business was (OH8)? Was it a (READ KEY)?	HO24
Code(industry)	
Other(specify)	
What did (COMPANY) make, or what service did they provide?	OH25
(Industry description/Same as OH24)	
What were your main activities or duties as a (JOB TITLE) at (COMPANY)?	OH26
	· · · · · · · · · · · · · · · · · · ·

(Duties)

What kinds of chemicals or materials did you handle in that job?	ОН27
(Chemicals/Materials)	
You said you worked as a (OH13) from (OH14) to (OH15) at (OH12). What type of business was (OH12)? Was it a (READ KEY)?	OH28
Code(industry)	
Other(specify)	
What did (COMPANY) make, or what service did they provide?	OH29
(Industry description/Same as OH28)	
What were your main activities or duties as a (JOB TITLE) at (COMPANY)?	ОН30
(Duties)	

What kinds of chemicals or materials did you handle in that job?	ОН31
(Chemicals/Materials)	
(Chombais Materials)	
You said you worked as a (OH17) from (OH18) to (OH19) at (OH16). What type of business was (OH16)? Was it a (READ KEY)?	ОН32
Code(industry)	
Other (specify)	
What did (COMPANY) make, or what service did they provide?	ОН33
(Industry description/Same as OH32)	
What were your main activities or duties as a (JOB TITLE) at (COMPANY)?	ОН34
(Duties)	

What kinds of chemicals or materials did you handle in that job?			ОН35
	(Chemicals/Materials)		
What kinds of tools and equipment did you use?			ОН36
	(Tools/Equipment)		
How many months per year did you work on this job?	•		ОН37
	(months/year)		÷
On average, about how many hours per week did you work on this	job?		ОН38
	(hours/week)	
While on this job, did you ever work near diesel or other types of en or did you smell diesel or other types	gines of exhaust?		ОН39
	1 2 98 99	No DK	

How did you commute to this job? IF >1 MEANS, PROBE FOR PRIMAL	RY	OH40
(OR THAT WAS FOR LONGEST DISTANCE OR TIME) AND RECOR ADDITIONAL MEANS IN SPACES I	D PROVIDED.	
1 Bus/Tramway		
2 Metro/Train		·
3 Car		
4 Bicycle		
5 Motorcycle		
6 Foot		
7 Animal		
8 Other	•	
(specify)		
98 DK (skip to OH57) 99 R (skip to OH57)		
99 K (Skip to OH37)	4.	
What kinds of tools and equipment did you use?		OH41
	(Tools/Equipment)	
How many months per year did you work on this job?		OH42
	(months/year)	

On average, about how many hours per week did you work on this job?	·	ОН43
(ho	ours/week)	
While on this job, did you ever work near diesel or other types of engines or did you smell diesel or other types of exhaust?		ОН44
	1	
How did you commute to this job? IF >1 MEANS, PROBE FOR PRIMARY (OR THAT WAS FOR LONGEST DISTANCE OR TIME) AND RECORD ADDITIONAL MEANS IN SPACES PROVIDED).	OH45
1 Bus/Tramway 2 Metro/Train 3 Car 4 Bicycle 5 Motorcycle 6 Foot 7 Animal 8 Other	,	
What kinds of tools and equipment did you use?		ОН46
(Tools/Equi	pment)	

How many months per year did you work on this job?	OH47
(months/year)	
On average, about how many hours per week did you work on this job?	ОН48
(hours/week)	
While on this job, did you ever work near diesel or other types of engines or did you smell diesel or other types of exhaust?	ОН49
1 2 98 99	☐ Yes☐ No☐ DK☐ R
How did you commute to this job? IF >1 MEANS, PROBE FOR PRIMARY (OR THAT WAS FOR LONGEST DISTANCE OR TIME) AND RECORD ADDITIONAL MEANS IN SPACES PROVIDED.	OH50
1 Bus/Tramway 2 Metro/Train 3 Car 4 Bicycle 5 Motorcycle 6 Foot 7 Animal 8 Other	
(specify) 98 DK (skip to OH67) 99 R (skip to OH67)	

What kinds of tools and equipment did you use?		OH51
	(Tools/Equipment)	
How many months per year did you work on this job?		OH52
	(months/year)	
On average, about how many hours per week did you work on this	job?	ОН53
	(hours/week)	
While on this job, did you ever work near diesel or other types of en or did you smell diesel or other types		ОН54
	1	

How did you commute to this job? IF >1 MEANS, PROBE FOR PRIMARY (OR THAT WAS FOR LONGEST DISTANCE OR TIME) AND RECORD ADDITIONAL MEANS IN SPACES PROVID	ED.	OH55
1 Bus/Tramway 2 Metro/Train 3 Car 4 Bicycle 5 Motorcycle 6 Foot 7 Animal 8 Other		
How long did it take you to get to this job, one way, from your house? (ENTER HOURS AND MINUTES.)	(code (hours) (minutes)	OH56
At this job, on average, about how many people around you smoked?	0	ОН57

Was your work at this job mostly indoors, mostly outdoors, or about the same amount indoors and outdoors?						OH58
	1 2 3 98 99		Mostly In Mostly O Both Indo DK R	utdo	ors	tdoors
What was the primary source of drinking water when you worked there?	:					OH59
	1 2 3 4 5 98 99		Municipa Well Spring Bottled Other DK R	al wa	ter supp	ply
In this job, did you ever have to regularly pass long hours without being able to uring TO MODULE, IF APPLICABLE. OTHERWISE, GO BACK TO OH20 FO	nate?		JOB.			ОН60
NOTE: IF <u>BOTH</u> AN INDUSTRY MODELETTER CODE, ENDING IN "I") <u>AND</u> MODULE (2 LETTER CODE) APPLY TO JOB, COMPLETE ONLY THE JOB MODELETE ONLY THE JOB MODELET	A J(O O	OB NE				
			1 2 98 99		Yes No DK R	

How long did it take you to get one way, from your house? (ENTER HOURS AND MINU	·
	(code total minutes)————————————————————————————————————
	(minutes)
At this job, on average, about how many people around you	smoked?
·	0
Was your work at this job moi indoors, mostly outdoors, or a same amount indoors and out	bout the
•	1 Mostly Indoors 2 Mostly Outdoors 3 Both Indoors and Outdoors 98 DK 99 R
What was the primary source drinking water when you wor	of OH64 OH64
	1

In this job, did you ever have to regularly pass long hours without being able to urinate? GO TO MODULE, IF APPLICABLE. OTHERWISE, GO BACK TO OH20 FOR NEX	Т ЈОВ.
NOTE: IF <u>BOTH</u> AN INDUSTRY MODULE (3 LETTER CODE, ENDING IN "I") <u>AND</u> A JOE MODULE (2 LETTER CODE) APPLY TO ONE JOB, COMPLETE ONLY THE JOB MODULE.	E
	1
How long did it take you to get to this job, one way, from your house? (ENTER HOURS AND MINUTES.)	(code total minutes) (minutes)
At this job, on average, about how many people around you smoked?	OH67 0
Was your work at this job mostly indoors, mostly outdoors, or about the same amount indoors and outdoors?	Mostly Indoors Mostly Outdoors Both Indoors and Outdoors DK

What was the primary source of drinking water when you worked there?		ОН69
1 2 3 4 5 98 99	Municipal water su Well Spring Bottled Other DK R	ipply
In this job, did you ever have to regularly pass long hours without being able to urinate GO TO MODULE, IF APPLICABLE. OTHERWISE, GO BACK TO OH20 FOR N		ОН70
NOTE: IF <u>BOTH</u> AN INDUSTRY MODULE LETTER CODE, ENDING IN "I") <u>AND</u> A C MODULE (2 LETTER CODE) APPLY TO (JOB, COMPLETE ONLY THE JOB MODU	ONE	
JOB, COMILETE ONET THE COD MODE	1 Yes 2 No 98 DK 99 R	
How long did it take you to get to this job, one way, from your house? (ENTER HOURS AND MINUTES.)		OH71
	(hours)	(code total minutes)
	(minutes)	

At this job, on average, about how many people around you smoked?	ОН72
	0
Was your work at this job mostly indoors, mostly outdoors, or about the same amount indoors and outdoors?	OH73 1
What was the primary source of drinking water when you worked there?	OH74 1
	5 Other 98 DK

, Breast Cancer Risk Study; ver4. January 21, 1999

In this job, did you ever have to regularly pass long hours without being able to urinate? GO TO MODULE, IF APPLICABLE. OTHERWISE, GO BACK TO OH20 FOR NEXT JOB.

OH75

NOTE: IF <u>BOTH</u> AN INDUSTRY MODULE (3 LETTER CODE, ENDING IN "I") <u>AND</u> A JOB MODULE (2 LETTER CODE) APPLY TO ONE JOB, COMPLETE ONLY THE JOB MODULE.

> 1 Yes 2 No 98 DK 99 R

END OF JOB HISTORY

OCCUPATIONAL EXPOSURE

Have you ever been exposed, either on the jour off, to any of the following substances or processes for a lifetime total of a year or more?	ob	OC3	
EXAMPLE: If you have been exposed to a substance for 2 months at a time for 6 years or more, that constitutes a lifetime total of a year or more. Have you ever been exposed to ASBESTOS			
	1 Yes *2 No *98 DK *99 R	·	
How long were you exposed to this substance?	0 Less than 1 year 1-70 Years 98 DK 99 R	OC3a	
Were you exposed to this substance at one of the jobs previously listed?	1 Yes, specify job title [sp	OC3b	
	2 No 98 DK 99 R		
Have you ever been exposed to DIESEL FUEL or EXHAUST (for a year or more)?		OC4	
*Interviewer : [go to OC5]	1 Yes *2 No *98 DK *99 R		

Breast Cancer Risk Study; ver4. January 21, 1	999	'31
How long were you exposed to this substance?	0	OC4a
Were you exposed to this substance the jobs previously listed?	at one of 1 Yes, specify job title [specify] 2 No 98 DK 99 R	ОС4Ь
Have you ever been exposed to GAS or GASOLINE EXHAUST (for a ye more)? *Interviewer: [go to OC6]		OC5
How long were you exposed to this substance?	0	OC5a
Were you exposed to this substance the jobs previously listed?	e at one of 1 Yes, specify job title [specify] 2 No 98 DK 99 R	ОС5Ъ

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Breast Cancer Risk Study; ver4. January 21, 1999	
Have you ever been exposed to DYESTUFFS (material or cloth (for a year or more)?	ning dyes)
1 ☐ Yes *2 ☐ No *98 ☐ DK	
*99	
*Interviewer: [go to OC7]	
How long were you exposed to this	OC6a
substance? 0 Less than 1 year	OCoa
1-70 Years	
98 DK 99 R	
Were you exposed to this substance at one of the previously jobs listed?	OC6b
1	title [specify]
Have you ever been exposed to ORGANIC	
SOLVENTS (for a year or more)? (Interviewer: show respondent card B)	OC7
1 Yes *2 No *98 DK	
*99	
How long were you exposed to this substance?	OC7a
0 Less than 1 year	
1-70 Years	
98 □ DK	

Were you exposed to this substance at one of the jobs previously listed? 1 Yes, specify job title [specify] 2 No 98 DK 99 R	ОС7Ь
Have you ever been exposed to DDT (for a year or more)? 1 Yes *3 No *98 DK *99 R	OC8
*Interviewer: [go to OC9] How long were you exposed to this	
0 Less than 1 year 1-70 Years 98 DK 99 R	OC8a
Were you exposed to this substance at one of the jobs previously listed? 1 Yes, specify job title [specify]	OC8b
2	
Have you ever been exposed to HERBICIDES (for a year or more)?	OC9
1 Yes *2 No *98 DK *99 R	
*Interviewer: [go to OC10]	

Breast Cancer Risk Study; ver4. January 21, 1999 How long were you exposed to this OC9a substance? 0 Less than 1 year Years 1-70 DK 98 99 [$\exists R$ Were you exposed to this substance at one of ОС9Ъ the jobs previously listed? Yes, specify job title [specify] 1 2 No 98 DK 99 R Have you ever been exposed to INSECTICIDES OC10 (for a year or more)? Yes 1 *2 No *98 DK ***99** R *Interviewer: [go to OC11] How long were you exposed to this substance? OC10a Less than 1 year 0 1-70 Years DK 98 99 R Were you exposed to this substance at one of the jobs previously listed? OC10b Yes, specify job title [specify] 1 2 No DK 98 R99 [

Breast Cancer Risk Study; ver4. January 21, 1999	, 35
Have you ever been exposed to PAINTS (for a year or more)?	OC11
1 Yes *2 No *98 DK *99 R	
*Interviewer : [go to OC12]	
How long were you exposed to this substance?	OC11a
0	
Were you exposed to this substance at one of the jobs previously listed?	OC11b
1 Yes, specify job title [specify] 2 No 98 DK 99 R	
Have you ever been exposed to PAINT THINNERS (for a year or more)? 1	OC12
How long were you exposed to this substance? 0 Less than 1 year 1-70 Years 98 DK 99 R	OC12a

Were you exposed to this substance at one of the jobs previously listed?	OC12b
1 Yes, specify job title [specify] 2 No 98 DK 99 R	
Have you ever been exposed to MINERAL, CUTTING, or LUBRICATING OIL (for a year or more)?	OC13
1 Yes *2 No *98 DK *99 R	
*Interviewer :[go to OC14]	
How long were you exposed to this substance?	OC13a
0	
Were you exposed to this substance at one of the jobs previously listed?	OC13b
1 Yes, specify job title [specify] 2 No 98 DK 99 R	
Have you ever been exposed to COAL, TAR, SOOT, PITCH, CREOSOTE, or ASPHALT (for a	OC14
year or more)? 1 Yes *2 No	
*98	

Breast Cancer Risk Study; ver4. January	21, 1999	37.
*Interviewer :[go to OC15]		,
How long were you exposed to t substance?	0	OC14a
Were you exposed to this substathe jobs previously listed?	ance at one of	OC14b
	1 Yes, specify job title [specify] 2 No 98 DK 99 R	
Have you ever been exposed to RUBBER or CABLE MAKING (for a year or more)? *Interviewer : [go to OC16]	NG 1	OC15
How long were you exposed to the Substance?	this 0	OC15a
Were you exposed to this substathe jobs previously listed?	1 Yes, specify job titl	OC15b
	2 No 98 DK 99 R	

Have you ever been exposed to PRINTING INKS (for a year or more)?	1 Yes *2 No *98 DK	OC16
*Interviewer: [go to O17]	*99 🔲 R	
How long were you exposed to this substance?		OC16a
	0	
Were you exposed to this substance at one of the jobs previously listed?		OC16b
	1 Yes, specify job title 2 No 98 DK 99 R	e [specify]
Have you ever been exposed to PLASTIC PRODUCTION (for a year or more)?		OC17
*Interviewer: [go to OC18]	1 Yes *2 No *98 DK *99 R	
		OC17a
How long were you exposed to this substance?		001/4
	0	

Were you exposed to this substance at one of the jobs previously listed?		OC17b
	1 Yes, specify job title 2 No 98 DK 99 R	e [specify]
Have you ever been exposed to LEATHER PRODUCTION (for a year or more)?		OC18
*Interviewer: [go to OC19]	1 Yes *2 No *98 DK *99 R	
How long were you exposed to this substance?		OC18a
	0 Less than 1 year 1-70 Years 98 DK 99 R	
Were you exposed to this substance at one of the jobs previously listed?		OC18b
	1 Yes, specify job title 2 No 98 DK 99 R	e [specify]
Have you ever been exposed to LUMBER INDUSTRY or WOOD DUST(for a year or m	iore)?	OC19
Interviewer: [go to OC20]	1 Yes *2 No *98 DK *99 R	

How long were you exposed to this substance?		OC19a
	0	
Were you exposed to this substance at one the jobs previously listed?	of	OC19b
. :	1 Yes, specify job title 2 No 98 DK 99 R	e [specify]
Have you ever been exposed to GLUE OR ADDITIVES (for a year or more)?	1 ☐ Yes *2 ☐ No *98 ☐ DK	OC20
*Interviewer: [go to OC21]	*99	
How long were you exposed to this substance?		OC20a
	0	
Were you exposed to this substance at one the jobs previously listed?	of	OC20b
	1 Yes, specify job title 2 No 98 DK 99 R	e [specify]

1 [2 [

98 99 No DK

R

Yes, specify job title [specify]

END OF EXPOSURE SECTION

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The next series of questions will be about your diet. The year before [Ref Date] did you change your diet?	DTX2
	 Yes [go to DCHG] No DK R go to mfil]
[Interviewer if diet has changed in last year, use the prior year for the questionnaire. [For instance if this is 1998, but diet changed, use 1997. If diet did not change, use 1997.]	
The next questions ask about your use and preparation of meat and eggs during	D001
I will ask the number of times you ate the food items as well as how they were prepared. Some of the information may be hard to remember. Please try to give your most accurate estimation. Common methods of cooking include pan-frying, deep frying, oven broiling, baking, grilling, and microwaving. Interviewer: show card C	
During, how often did you eat eggs?	DO2a
Interviewer: show card D	1 Never [go to DO3a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

How many eggs did you usually eat per serving?	DO2b
serving:	1-80enter number 98
During, when you ate eggs, how often were they pan-fried, such as sunny side-up?	DO2c
Interviewer: show card D	
	 Never Less than once per month Once per month 2-3 times per month Once per week Twice per week 3-4 times per week 5-6 times per week Once per day Two or more times per day DK R
During, when you ate eggs, how often were they prepared in any other way? Interviewer: other than pan-fried	DO2d
Interviewer: show card D	Dever Less than once per month Once per month Conce per week Twice per week Twice per week Self Self times per week Tonce per day Two or more times per day Reserved Reserved Less than once per month Conce per week Twice per week Twice per week Twice per week The conce per day Two or more times per day Reserved Reserv
	yy

During, how often did you eat hamburgers and cheeseburgers including fast food?		DO3a
Interviewer: show card D		
11 12 12 13 14 15 19 99	Once per month Once per month Once per week Twice per week Once per week Solution 3-4 times per week Once per day Once per day Two or more times per day DK	,
What was your usual serving size of hamburgers and cheeseburgers? Interviewer: compared to this example 1-8 9	8 DK	DO3b
1 1 1 1 1	? 1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 1 Twice per week 3 3-4 times per week 5 5-6 times per week 7 Once per day 9 Two or more times per day 18 DK 19 R	

During, when you ate hamburgers and cheeseburgers, how often were they grilled or barbecued? Interviewer: show card D	DO3d
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per week 19 Two or more times per day 98 DK 99 R
During, when you ate hamburgers and cheeseburgers, how often were they oven-broiled ?	DO3e
Interviewer: show card D	1 ☐ Never
	3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

During, when you ate hamburgers and cheeseburgers, how often were they prepared in a way that I haven't mentioned? Interviewer: show card D	DO3f
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, how often did you eat beef steaks? Interviewer: show card D	DO5a Never [go to D07a] Less than once per month Once per month Conce per week The Twice per week The Twice per week The Section of the Sect
What was your usual serving size of beef steaks? Interviewer: compared to this example	DO5b 1-80oz 98

During, when you ate beef steaks, how often were they pan-fried ? Interviewer: show card D	DO5c Never Sees than once per month
During, when you ate beef steaks, how often were they grilled or barbecued? Interviewer: show card D	DO5d Never Less than once per month Conce per month Conce per month Conce per week Twice per week Twice per week Set once per week Conce per day Two or more times per day Conce per da

,Breast Cancer Risk Study; ver4. January 21, 1999	48
During, when you ate beef steaks, how often were they oven-broiled? Interviewer: show card D	DO5e
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you ate beef steaks, how often were they prepared in a way that I haven't mentioned? Interviewer: show card D	DO5f
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

Breast Cancer Risk Study; ver4. January 21, 1999	.49
During, how often did you eat pork chops or ham steaks? Interviewer: show card D	
	Never [go to D08a] Less than once per month Once per month Once per week Twice per week Twice per week S-6 times per week Once per day Two or more times per day R
What was your usual serving size of pork chops or ham steaks? Interviewer: compared to this example	DO7b
	1-80oz 98
During, when you ate pork chops or ham steaks, how often were they pan-fried? Interviewer: show card D	DO7c
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

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During, when you ate pork chops or ham steaks, how often were they oven-broiled? Interviewer: show card D	DO7d
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you ate pork chops or ham steaks, how often were they baked or roasted? Interviewer: show card D	DO7e
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

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Breast Cancer Risk Study; ver4. January 21, 1999	·51 °
During, when you ate pork chops or ham steaks, how often were they prepared in a way that I haven't mentioned? Interviewer: show card D	DO7f
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, how often did you eat bacon? Interviewer: show card D	D08a
	 Never [go to D09a] Less than once per month Once per month 2-3 times per month Once per week Twice per week 3-4 times per week 5-6 times per week Once per day Two or more times per day DK R
What was your usual serving size of bacon? Interviewer: in number of strips	DO8b
	1-80 strips 98

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During	, when you ate bacon how often		DO8c
was it Pan			
	: show card D	1 Never 3 Less than once per me 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per 98 DK 99 R	
	•	_	
was it gril	, when you ate bacon, how often led or barbecued ? r: show card D	 Never Less than once per m 	DO8d
		5 Once per month	
		7 2-3 times per month	
		9 Once per week 11 Twice per week	
		13 3-4 times per week	
		15 5-6 times per week	
		17 Once per day	er day
		19 ☐ Two or more times p 98 ☐ DK	ci day
		99 🔲 R	

During, when you ate bacon, how often was it oven-broiled? Interviewer: show card D	DO8e
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you ate bacon, how often was it microwaved? Interviewer: show card D	DO8f
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

Breast Cancer Risk Study; ver4. January 21, 1999	
During, when you ate bacon, how often was it prepared in a way that I haven't mentioned? Interviewer: show card D	DO8g
Interviewer. Snow cara D	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, how often did you eat sausage (including breakfast, Italian, Polish, and bratwurst)? Interviewer: show card D	DO9a
	 Never [go to D10a] Less than once per month Once per month 2-3 times per month Once per week Twice per week 3-4 times per week
	 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week
What was your usual serving size of sausage? Interviewer: 1 large or 2 small as a serving	1 Less than once per month Conce per month Conce per month Conce per week Twice per week Conce per week Conce per week Conce per week Conce per day Conce per month Conce per week Conce

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During, when you ate sausage, how often was it pan-fried? Interviewer: show card D	. DO9c
There were show cara D	1
During, when you ate sausage, how often was it grilled or barbecued? Interviewer: show card D	DO9d
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

Breast Cancer Risk Study; ver4. January 21, 1999	56
During, when you ate sausage, how often was it oven-broiled?	DO9e
Interviewer: show card D	
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you ate sausage, how often was it microwaved? Interviewer: show card D	DO9f
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

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Breast Cancer Risk Study; ver4. January 21, 1999	,57 <i>.</i>
During, when you ate sausage, how often was it prepared in a way that I haven't mentioned? Interviewer: show card D	D09g
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, how often did you eat hot dogs or franks? Interviewer: show card D	D10a
	1 Never [go to D11a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
What was your usual serving size of hot dogs or franks? Interviewer: in number of hot dogs	D10b
	1-80 hot dogs 98 DK 99 R

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Breast Cancer Risk Study; ver4. January 21, 1999	
During, when you ate hot dogs or franks, how often were they pan-fried? Interviewer: show card D	D10c
	 Never [go to D26a] Less than once per month Once per month 2-3 times per month Once per week Twice per week Twice per week 3-4 times per week 5-6 times per week Once per day Two or more times per day DK R
During, when you ate hot dogs or franks, how often were they oven-broiled? Interviewer: show card D	D10d
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

17 [

19

98

99

Once per day

] DK] R

Two or more times per day

Breast Cancer Risk Study; ver4. January 21, 1999		60
During, how often did you eat fried chicke Interviewer: show card D	n?	D11a
	1 Never [go to D12a] 3 Less than once per m 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times p 98 DK 99 R	
What was your usual serving size of fried chicken? Interviewer: compared to these examples		D11b
	1-80oz 98	
During, when you ate fried chicken, how often was it deep fat fried/fast food?		D11c
Interviewer: show card D		
	1 Never 3 Less than once per m 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times p 98 DK 99 R	

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Breast Cancer Risk Study; ver4. January 21, 1999	,61 ·
During, when you ate fried chicken, how often was it pan fried ?	D11d
Interviewer: show card D	
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
Other than fried chicken, during, how often did you eat chicken or turkey (including on sandwiches)? Interviewer: show card D	D12a
	Never [go to D13a] Less than once per month Once per month Conce per week Twice per week Twice per week Conce per day Conce
What was you usual serving size of the chicken or turkey? Interviewer: compared to this example 1 serving = 2 oz.	D12b 1-80 servings 98

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Breast Cancer Risk Study; ver4. January 21, 1999 During, when you ate chicken or turkey, how often was it baked or roasted? Interviewer: show card D	D12c
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you ate chicken or turkey, how often was it stewed? Interviewer: show card D	D12d
	 Never Less than once per month Once per month 2-3 times per month Once per week Twice per week Twice per week 3-4 times per week 5-6 times per week Once per day Two or more times per day

·63 ·
D12e
1
D12f
1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

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Breast Cancer Risk Study; ver4. January 21, 1999	
During, when you ate chicken or turkey, how often was it prepared in a way that I have not mentioned? Interviewer: show card D	D12g
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, how often did you eat fried fish or fish sandwiches (including other fried seafood) ? Interviewer: show card D	D13a
	1 Never [go to D14a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day
	19 Two or more times per day 98 DK 99 R
What was your usual serving size of fried fish or fish sandwich? Interviewer: compared to these examples	D13b

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During, when you ate fried fish or a	
fish sandwich, how often were they pan-	D13c
fried ?	
Interviewer: show card D	
	1 Never
	3 Less than once per month
	5 Once per month
	7 7 2-3 times per month
	9 Once per week
	11 Twice per week
·	13 3-4 times per week
	15 5-6 times per week
	17 Once per day
	19 Two or more times per day
	98
	99
. :	
During, when you ate fried fish or a fish sandwich, how often were they deep fat fried or fast food? Interviewer: show card D	D13d
inerviewer. Show cara D	
	1 Never
	3 Less than once per month5 Once per month
	F
	- Lance Francisco
	11 Twice per week 13 3-4 times per week
	15 5-6 times per week
·	17 Once per day
	19 Two or more times per day
	98 DK
	99 R
	77 I IIX

Breast Cancer Risk Study; ver4. January 21, 1999	66	
During, how often did you eat other fish besides fried fish (including tuna and shrimp)? Interviewer: show card D	D14a Never [go to D15a] Less than once per month Once per month Tolerant Twice per week Twice per week Jack Jack Jack Jack Jack Jack Jack Jack	
What was your usual serving size of other fish besides fried fish? Interviewer: compared to these examples	1-80oz 98	
During,when you ate other fish besides fried fish, how often was it oven-broiled? Interviewer: show card D	D14c Never Less than once per month Once per month Less times per month	
	9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R	

During, when you ate other fish besides fried fish, how often was it baked? Interviewer: show card D	D14d
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you ate other fish besides fried fish, how often was it in a casserole? Interviewer: show card D	D14e
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

	, when you ate other fish besides ow often was it in a salad? show card D	[1	D14f
		1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per da 98 DK 99 R	y
fried fish, he that I have	when you ate other fish besides ow often was it prepared in a way not mentioned? show card D	Ī	D14g

During, how often did you eat roast beef (including sandwiches)? Interviewer: show card D	D15a
	1 Never [go to D16a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
What was your usual serving size of roast beef? Interviewer: compared to these examples	D15b 1-80oz 98
During, how often did you eat beef stew or potpie with carrots or other vegetables? Interviewer: show card D	D16a Never [go to D17a] Less than once per month Once per month Once per week Twice per week Twice per week S-6 times per week Once per day Two or more times per day R

1-80oz 98
D17a
 Never [go to D18a] Less than once per month Once per month 2-3 times per month Once per week Twice per week Twice per week 3-4 times per week 5-6 times per week Once per day Two or more times per day DK R
D17b

During, how often did you eat meat gravies made with meat drippings? Interviewer: show card D	D18a
	1 Never [go to D19a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
What was your usual serving size of meat gravies? Interviewer: compared to this example of 2 tablesp	D18b
	1-80teaspoons 98
During, how often did you eat ham, bologna, salami, and other lunch meats? (Not including chicken, turkey or roast beef) Interviewer: show card D	D19a
	1 Never [go to D20a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R

	D19b	
1-80oz 98		
	D20a	
5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day	•	
	D20b	
oz DK] R		*
	98 DK 99 R 1 Never [go to D21a] 3 Less than once per m 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per month 98 DK 99 R	1-80

Breast Cancer Risk Study; ver4. January 21, 1999		.73.
During, how often did you eat soups containing meat such as vegetable beef, chicken, etc? Interviewer: show card D	1 Never [go to D22a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R	D21a
What was your usual serving size of sour containing meat such as vegetable beef, chicken, etc? Interviewer: 1 cup = 8 ounces	1-80oz 98DK 99R	D21b
During, how often did you eat toast any meal? Interviewer: show card D	Never [go to D23a] Less than once per month Conce per month Conce per week Twice per week Twice per week S-6 times per week Conce per day Two or more times per day R	D22a

Breast Cancer Risk Study; ver4. January 21, 1999		
What was your usual serving size of toast ? Interviewer: in number of slices		D221
	-80 (slices) 98	
During, when you ate the toast, how was it usually toasted ? Interviewer: show card D-2		D22c
· · · · · · · · · · · · · · · · · · ·	 Did not eat Light Medium Dark 	
•	9	
During, how often did you eat fried bread (2 hushpuppies = 1 slice)?	• :	D23a
Interviewer: show card D and D-3		
Interviewer: show card D and D-3	1 Never [go to D24a] 3 Less than once per month 5 Once per month 7 2-3 times per month	
Interviewer: show card D and D-3	3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week	
Interviewer: show card D and D-3	3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week	
What was your usual serving size of fried bread (2 hushpuppies = 1 slice)? Interviewer: in number of slices	3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK	D23b

Breast Cancer Risk Study; ver4. January 21, 1999		• 75
During, how often did you eat fats on bread that were saved after cooking, for example, bacon fat? Interviewer: show card D	D24a _	
Interviewer: snow cara D	1 Never [go to D26a] 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R	
What were your usual serving size of fats on bread that were saved after cooking? Interviewer: In number of slices	D24b	
	1-80Slices 98 DK 99 R	
During, when you ate hamburgers or cheeseburgers, how were they usually cooked? Interviewer: show card D-4	D26	
Imerviewer. Snow cara D-4	1 Did not eat 3 Rare 5 Medium rare 7 Medium 9 Medium well 11 Well-done 13 Very well-done 98 DK 99 R	

During, when you ate steak, how was it usually cooked?		D27
Interviewer: show card D-4	1 Did not eat 3 Rare 5 Medium rare 7 Medium 9 Medium well 11 Well-done 13 Very well-done 98 DK 99 R	-
During, when you ate chicken, how was it usually cooked? Interviewer: show card D-5	1 Did not eat	D28
· .	3 Just until done 5 Well-done 7 Very well-done 98 DK 99 R	
During, when you ate pork chops or ham steaks, how was it usually cooked? Interviewer: show card D-5		D29
	1 Did not eat 3 Just until done 5 Well-done 7 Very well-done 98 DK 99 R	
During, when you ate hot dogs or franks, how were they usually cooked? Interviewer: show card D-6		D30
Individual State Cut to D-V	1 Did not eat 3 Just until done 5 Well-done/crisp 7 Charred 98 DK 99 R	

Breast Cancer Risk Study; ver4. January 21, 1999		,77.
During, when you ate bacon, how was it usually cooked? Interviewer: show card D-6		D31
	1 Did not eat 3 Just until done 5 Well-done/crisp 7 Charred 98 DK 99 R	
During, when you ate sausage, how was it usually cooked? Interviewer: show card D-6		D32
	1 Did not eat 3 Just until done 5 Well-done/crisp 7 Charred 98 DK 99 R	
During, when you ate gravies how were they usually cooked?		D33
	1 Did not eat 3 Made from meat dripp 5 Store bought cans 7 Store bought packets 98 DK 99 R	pings

During, how often did you use the fat from fried bacon in your cooking? Interviewer: show card D	D34
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
In the summer months, how often did you eat grilled or barbecued meats (including beef, pork, chicken, or fish)? Interviewer: show card D	D35 Never Less than once per month Once per month Once per week Twice per week Twice per week S-6 times per week Tonce per day Two or more times per day R DX
	98 🗍 DK

did you eat grilled or barbecued meats (including beef, pork, chicken, or fish)? Interviewer: show card D	D36
	1 Never 3 Less than once per month 5 Once per month 7 2-3 times per month 9 Once per week 11 Twice per week 13 3-4 times per week 15 5-6 times per week 17 Once per day 19 Two or more times per day 98 DK 99 R
During, when you had grilled or barbecued meats, how often were they charred? Interviewer: show card D-7	D37 1 Never 3 About ¼ of the time 5 About ½ of the time 7 About ¾ of the time 9 About 100% of the time 11 Did not eat grilled or barbecued meats 98 DK 99 R
During, when you had pan-fried or oven-broiled meats, how often were they well-browned? Interviewer: show card D-7	D38 Never About ¼ of the time About ½ of the time About ¾ of the time About 100% of the time Did not eat pan-fried or oven-broiled meats R B C C D38 D R

Now I would like you to look at some photographs of meats which have been cooked to different degrees. Please decide which photograph most closely resembles the way meat you eat is cooked. If you eat meat that looks to be between categories, you may indicate that. For example, you would select 2.5 to indicate that the meat you eat looks between pictures 2 and 3.

Let's start with beef. Please pay special attention to the way hamburger and steaks look inside as well as outside. For example, there is little difference in the internal appearances of the meat between numbers 3 and 4 for both hamburgers and steaks, but there is more browning and charring on the external surface of number 4 as compared to number 3.

During, when you ate the following items, which picture most closely resembles the way they were usually cooked? (Interviewer: show photograph of hamburgers and cheeseburger)	D40
	0 Did not eat
	1.0
	2.0
	3.0
	4.0
	98

During, when you ate the following items, which picture most closely resembles the way they were usually cooked? (Interviewer: show photograph of steaks)	D41
	0
During, when you ate the following items, which picture most closely resembles the way they were usually cooked?	D42
Interviewer: show photograph of ham steaks)	0

During, when you ate the following items, which picture most closely resembles the way they were usually cooked?	D43
(Interviewer: show photograph of pork chops)	0
During, when you ate the following items, which picture most closely resembles the way they were usually cooked?	D44
(Interviewer: show photograph of hot dogs)	0

During, when you ate the following items, which picture most closely resembles the way they were usually cooked? (Interviewer: show photograph of bacon)	D45
	0
	1.5
	3.0
	98

MEDICAL and FAMILY HISTORY

MEDICAL HISTORY:		
Now I am going to ask you some question About your medical and family history.	S	MH1
Since birth, have you ever had diabetes?	1 Yes 2 No (go to next section) 98 DK 99 R	
What was your age when you first learne that you had diabetes?	d	MH1
·	1 (enter age) 97	
Did you take insulin?	1 Yes 2 No 98 DK 99 R	MH1b

FAMILY HISTORY:

In this section of the questionnaire I would like to ask you about the health history of your immediate blood relatives. This would include your mother, father, sisters, brothers and children. I am interested in living and deceased members of your family, but I am interested only in your full blood relatives not half or adopted relatives.

I am going to start with your parents. Interviewer: Please read across. ie: complete questions about mother first then move to father.

Is your (Relative) still living?	How old is (HE/SHE) ?	How old was (HE/SHE) when (HE/SHE) died?
F001 Mother	F002 Mother	F003 Mother
1 Yes	ENTER AGE	ENTER AGE
2 No (go to F003)	98 DK (go to F004)	98 🔲 DK
98 DK (go to F004)		
F013 Father	F014 Father	F015 Father
l Yes	ENTER AGE*	ENTER AGE
2 No (go to F015)	98 DK*	98
98 DK (go to F016)	*(go to F016)	
Cancer Types (Interview		
1 Skin (not meland	oma) 12 Melanoma	
2 Lung	13 Oral Cavity	
3 Breast	14 Ovary	

<mark>ypes_</mark> (Interviewer: show o	ara	(E)
Skin (not melanoma)	12	Melanoma
Lung	13	Oral Cavity
Breast	14	Ovary
Colon	15	Pancreas
Prostate	16	Rectum
Bladder	17	Stomach
Brain	18	Uterus (corpus uteri)
Cervix	19	Other Cancer (specify)
Kidney	20	Cancer of female reproductive organs: site unknown
Leukemia	21	Cancer of the large bowel (colon/rectum) site unknown
Lymphoma	22	Relative had cancer; site unknown
	Skin (not melanoma) Lung Breast Colon Prostate Bladder Brain Cervix Kidney Leukemia	Lung 13 Breast 14 Colon 15 Prostate 16 Bladder 17 Brain 18 Cervix 19 Kidney 20 Leukemia 21

Was your (Relative) ever diagnosed as having any type of cancer?	What was the first type of cancer your (Relative) had?	How old was (HE/SHE) when this cancer was diagnosed?
F004 Mother 1 Yes 2 No (go to F025a) 98 DK (go to F025a)	Write cancer name and # (see list above)	F006 Mother enter age 00 <1 year old 98 DK
F016 Father 1 Yes 2 No (go to F025a) 98 DK (go to F025a)	write cancer name and # (see list above)	F018 Father enter age 00 <

Cancer Ty	<u>pes</u>		
1	Skin (not melanoma)	12	Melanoma
2	Lung	13	Oral cavity
3	Breast	14	Ovary-
4	Colon	15	Pancreas
5	Prostate	16	Rectum
6	Bladder	17	Stomach
	Brain	18	Uterine (corpus uteri)
8	Cervix	 19	Other cancer (specify)
_	Kidney	20	Cancer of female reproductive organs, site unknown
10	Leukemia	21	Cancer of the large bowel (colon/rectum) site unknown
11	Lymphoma	22	Relative had cancer, site unknown

Did your (RELATIVE) have any other cancer?	What was the next type of cancer your (RELATIVE) had?	How old was (HE/SHE) when this cancer was diagnosed?	
F007 Mother 1 Yes	F008 Mother	F009 Mother enter age 00	
2 No (go to F020) 98 DK (go to F020)	write cancer name and # (see list above)	98 DK	
F019 Father 1 Yes 2 No (go to FTX1) 98 DK (go to FTX1)	F020 Father write cancer name and # (see list above)	F021 Father enter age 00 <1 year old 98 DK	

Did your (RELATIVE) have any other cancer?	What was the next type of cancer your (RELATIVE) had?	How old was (HE/SHE) when this cancer was diagnosed?
F010 Mother	F011 Mother	F012 Mother enter age
1 Yes 2 No (go to F020) 98 DK (go to F020)	write cancer name and # (see list above)	00
F022 Father	F023 Father	F024 Father enter age
1 Yes 2 No (go to FTX1) 98 DK (go to FTX1)	write cancer name and # (see list above)	00

Now I would like to ask you the same questions about your <u>full</u> brothers and sisters. Please include those who are living or deceased, but do not include adopted, foster, half or step brothers and sisters.

How many full brothers and sisters do you have? Again, please include any who may have died.	FTX1
F025a brothersenter number 0 None 98 DK 99 R	F025a
F025b sisters enter number 0	F025b
Interviewer: Enter total number of siblings	_ (If number of siblings=0, FTX2)

Note: a response followed by an alphanumeric in brackets: (F000) indicates that if this response is given, the interviewer should proceed to the question described by the alphanumeric. Interviewers should complete each page from top to bottom before asking the next set of questions in the numeric sequence.

Interviewers please complete each page from top to bottom before asking the next set of questions in the numeric sequence. For example, complete name column first then go back to first sibling and ask questions across a row. In order to be consistent, it is important that each question be asked and each response be recorded in a similar manner. Therefore, all interviewers must follow the same technique.

	What are the first	What is	Is (name) still	How old is	How old was
	names of your	(names) sex?	living?	(name) ?	(name) when
	brothers or sisters?				(he/she) died?
	F026 oldest	F027	F028	F029	F030
	name	1 Male	1 Yes	enter age	enter age
1	98 DK (F027)	2 Female	2 No (F030)	98 DK (F031)	00 ──<1 year old
	99□ R	98 DK ·	98 DK (F031)	_	98 DK (F031)
	F040 next	F041	F042	F043	F044
	name	1 Male	1 Yes	enter age	enter age
2	00 None [nxt sec]	2 Female	2 No (F044)		00 < 1 year old
	98 DK (F041)	98 <u> </u>	98 DK (F045)	98 DK (F045)	98 DK (F045)
	F054 next	F055	F056	F057	F058
	name	1 Male	1 Yes	enter age	enter age
3	00 None [nxt sec]	2 Female	2 No (F058)		00 < 1 year old
	98 DK (F055)	98 □ DK	98 DK (F059)	98 DK (F059)	98 DK (F059)
	F068 next	F069	F070	F071	F072
	name	1 Male	1 Yes	enter age	enter age
4	00 None [nxt sec]	2 Female	2 No (F072)		00 < 1 year old
	98 DK (F069)	98 DK	98 DK (F073)	98 DK (F073)	98 DK (F073)
	F082 next	F083	F084	F085	F086
	name	1 Male	1 Yes	enter age	enter age
5	00 None [nxt sec]	2 Female	2 No (F086)		00_<1 year old
	98 DK (F083)	98 DK	98 DK (F087)	98 DK (F087)	98 DK (F087)
 	F096 next	F097	F098	F099	F100
	name	1 Male	1 Yes	enter age	enter age
6	00 None [nxt sec]	2 Female	2 No (F100)		00 < 1 year old
	98 DK (F097)	98 <u>□</u> DK	98 DK (F101)	98 DK (F101)	98 DK (F101)
	F110 next	F111	F112	F113	F114
	name	l Male	l Yes	enter age	enter age
7	00 None [nxt sec]	2 Female	2 No (F114)		00 < 1 year old
	98 DK (F111)	98∐ DK	98 DK (F115)	98 DK (F115)	98 DK (F115)

Interviewer: write the total number of siblings here:

Write in sibling's first names on following pages now.

[nxt sec] = medical history questions of children

Interviewer: write the total number of siblings here:

Cancer T	<u>ypes</u>		
1	Skin (not melanoma) 1	2	Melanoma
2	Lung 1	3	Oral cavity
3	Breast 1	4	Ovary
4	Colon 1	5	Pancreas
5	Prostate 1	6	Rectum
6	Bladder 1	7	Stomach
7	Brain 1	8	Uterine (corpus uteri)
8	Cervix 1	9	Other cancer (specify)
9	Kidney 2	0	Cancer of female reproductive organs: site unknown
10	Leukemia 2	1	Cancer of the large bowel (colon/rectum), site unknown
11	Lymphoma 2	2	Relative had cancer: site unknown

	Was (first name) ever diagnosed	What was the first type of cancer	How old was (HE/SHE)
	as having any type of cancer?	(NAME) had?	when this cancer was
			diagnosed?
1	F031	F032	F033
	1 Yes		enter age
	2 No (F040) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F040)	(see list above)	98 DK (F034)
2	F045	F046	F047
	1 Yes	·	enter age
	2 No (F054) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F054)	(see list above)	98 DK (F048)
3	F059	F060	F061
	1 Yes		enter age
	2 No (F068) sibling name	write in cancer name and #	- 00 <1 year old
	98 DK (F068)	(see list above)	98 DK (F062)
4	F073	F074	F075
	1 Yes		enter age
	2 No (F082) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F082)	(see list above)	98 DK (F076)
5	F087	F088	F089
	1 Yes		enter age
İ	2 No (F096) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F096)	(see list above)	98 DK (F090)
	_	, , , ,	
6	F101	F102	F103
	l Yes		enter age
	2 No (F110) sibling name	write in cancer name and #	00 <1 year old
1	98 DK (F110)	(see list above)	98 DK (F104)
		(555 1.55 555.5)	
7	F115	F116	F117
	1 Yes		enter age
1	2 No [Nxt Sec] sibling name	write in cancer name and #	- 00 <1 year old
	98 DK [Nxt Sec]	(see list above)	98 DK (F118)

Cancer Ty	pes		
1.	Skin (not melanoma)	12.	Melanoma
2.	Lung	13.	Oral Cavity
3.	Breast	14.	Ovary
4.	Colon	15.	Pancreas
5.	Prostate	16.	Rectum
6.	Bladder	17.	Stomach
7.	Brain	18.	Uterine (corpus uteri)
8.	Cervix	19.	Other cancer (specify)
9.	Kidney -	20.	Cancer of female reproductive organs; site unknown
10.	Leukemia	21.	Cancer of the large bowel (colon/rectum), site unknown

11. Lymphoma 22. Relative had cancer; site unknown

	Did (first name) have any other	What was the second type of cancer	How old was (HE/SHE)
	cancer?	(NAME) had?	when this cancer was
			diagnosed?
1	F034	F035	F036
1	1 Yes		enter age
	2 No (F040) sibling name	write in cancer name and #	00 < l year old
	98 DK (F040)	(see list above)	98 DK (F037)
2	F048	F049	F050
	1 Yes		enter age
	2 No (F054) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F054)	(see list above)	98 DK (F051)
3	F062	F063	F064
	1 Yes		enter age
	2 No (F068) sibling name	write in cancer name and #	00 <u> </u>
	98 DK (F068)	(see list above)	98 DK (F065)
4	F076	F077	F078
	1 Yes		enter age
	2 No (F082) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F082)	(see list above)	98 DK (F079)
5	F090	F091	F092
	1 Yes		enter age
1	2 No (F096) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F096)	(see list above)	98 DK (F093)
			7106
6	F104	F105	F106
	1 Yes		enter age
	2 No (F110) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F110)	(see list above)	98 DK (F107)
		F119	F120
7	F118	F117	enter age
1	1 Yes	**************************************	00 <1 year old
1	2 No [Nxt Sec] sibling name	write in cancer name and #	98 DK (F121)
<u></u>	98 DK [Nxt Sec]	(see list above)	1,000 2(1,12.)
Inter	rviewer: write the total number of	siblings here:	<u>.</u> •

``a	n	ce	r	$T_{\mathbf{y}}$	'n	es
_~		••	/ 5	-	,,,,,	vu

1.	Skin (not melanoma)	12. Melanoma
2.	Lung	13. Oral Cavity
3.	Breast	14. Ovary
4.	Colon	15. Pancreas
5.	Prostate	16. Rectum
6.	Bladder	17. Stomach
7.	Brain	18. Uterine (corpus uteri)
8.	Cervix	19. Other cancer (specify)
9.	Kidney	20. Cancer of female reproductive organs; site unknown
10.	Leukemia	21. Cancer of the large bowel (colon/rectum) site unknown
11.	Lymphoma	22. Relative had cancer; site unknown

	Did (first name) have any other	What was the third type of	How old was (HE/SHE)
	cancer?	cancer (NAME) had?	when this cancer was
			diagnosed?
1	F037	F038	F039
	l Yes		enter age
	2 No (F040) sibling name	write in cancer name and #	00 < 1 year old
	98 DK (F040)	(see list above)	98 DK (F040)
2	F051	F052	F053
	1 Yes		enter age
	2 No (F054) sibling name	write in cancer name and #	00 < 1 year old
	98 DK (F054)	(see list above)	98 DK (F054)
3	F065	F066	F067
	1 Yes		enter age
	2 No (F068) sibling name	write in cancer name and #	00 < 1 year old
	98 DK (F068)	(see list above)	98 DK (F068)
4	F079	F080	F081
	1 Yes		enter age
	2 No (F082) sibling name	write in cancer name and #	00 < 1 year old
	98 DK (F082)	(see list above)	98 DK (F082)
5	F093	F094	F095
	1 Yes		enter age
	3 No (F096) sibling name	write in cancer name and #	00 < 1 year old
	98 DK (F096)	(see list above)	98 DK (F096)
6	F107	F108	F109
	1 Yes		enter age
	2 No (F110) sibling name	write in cancer name and #	00 < 1 year old
	98 DK (F110)	(see list above)	98 DK (F110)
7	F121	F122	F123
	1 Yes		enter age
•	2 No [Nxt Sec] sibling name	write in cancer name and #	00 < 1 year old
	98 DK [Nxt Sec]	(see list above)	98 DK (F124)

Interviewers: write the total number of siblings here:

	What is the first	What is	Is (name) still	How old is	How old was
	name of your	(name) sex?	living?	(name)?	(name) when
	(next) brother or	,	J		(he/she) died?
	sister?				
8	F124	F125	F126	F127	F128
	name	1 Male	1 Yes	enter age	enter age
	00 None [NxtSec]	2 Female	2 No (F128)		00 <1 year old
	98 DK (F125)	98□ DK	98 DK (F129)	98. DK (F129)	98 DK (F129)
9	F138	F139	F140	F141	F142
	name	1 Male	1 Yes	enter age	enter age
	00 None [NxtSec]	2 Female	2 No (F142)		00 <u></u> <1 year old
	98 DK (F139)	98 DK	98 DK (F143)	98 DK (F143)	98 DK (F143)
10	F152	F153	F154	F155	F156
	name	1 Male	1 Yes	enter age	enter age
	00 None [NxtSec]	2 Female	2 No (F156)		00 < 1 year old
	98 DK (f153)	98□ DK	98 DK (F157)	98 DK (F157)	98 DK (F157)
11	F166	F167	F168	F169	F170
	name	l Male	1 Yes	enter age	enter age
	00 None [NxtSec]	2 Female	2 No (F170)	00 [] DV (E171)	00 <1 year old 98 DK (F171)
	98 DK (F167)	98□ DK	98 DK (F171)	98 DK (F171)	98 DK (F171)
12	F180	F181	F182	F183	F184
**	name	1 Male	1 Yes	enter age	enter age
	00 None [NxtSec]	2 Female	2 No (F184)		00 <1 year old
	98 DK (F181)	98∐ DK	98 DK (F185)	98 DK (F185)	98 DK (F185)
13	F194	F195	F196	F197	F198
	name	1 Male	1 Yes	enter age	enter age
1	00 None [NxtSec]	2 Female	2 No (F198)		00 < 1 year old
	98 DK (F195)	98∏ DK	98 DK (F199)	98 DK (F199)	98 DK (F199)
14	F208	F209	F210	F211	F212
	name	1 Male	1 Yes	enter age	enter age
	00 None [NxtSec]	2 Female	2 No (F212)		00 <1 year old
	98 DK (F209)	98 DK	98 DK (F213)	98 DK (F213)	98 DK (F213)

Interviewer: write the total number of siblings here:

11. Lymphoma

1.	Skin (not melanoma)	12.	Melanoma
2.	Lung	13.	Oral cavity
3.	Breast	14.	Ovary
4.	Colon	15.	Pancreas
5.	Prostate	16.	Rectum
6.	Bladder	17.	Stomach
7.	Brain	1 8 .	Uterine (corpus uteri)
8.	Cervix	19.	Other cancer (specify)
9.	Kidney	20.	Cancer of female reproductive organs; site unknown
10.	Leukemia	21.	Cancer of the large bowel (colon/rectum), site unknown

22. Relative had cancer, site unknown

	Was (first name) ever diagnosed as	What was the first type of	How old was (HE/SHE)
	having any type of cancer?	cancer (NAME) had?	when this cancer was
			diagnosed?
8	F129	F130	F131
	1 Yes		enter age
	2 No (F138) sibling name	write in cancer name and #	- 00 <1 year old
	98_DK (F138)	(see list above)	98 DK (F132)
9	F143	F144	F145
	1 Yes		enter age
	2 No (F152) sibling name	write in cancer name and #	- 00
	98∏DK (F152)	(see list above)	98 DK (F146)
10	F157	F158	F159
1	1 Yes		enter age
	2 No (F166) sibling name	write in cancer name and #	- 00 <1 year old
	98 DK (F166)	(see list above)	98 DK (F160)
11	F171	F172	F173
	1 Yes		enter age
	2 No (F180) sibling name	write in cancer name and #	_ 00
	98 DK (F180)	(see list above)	98 DK (F174)
12	F185	F186	F187
	1 Yes		enter age
	2 No (F194) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F194)	(see list above)	98 DK (F188)
13	F199	F200	F201
	1 Yes		enter age
	2 No (F208) sibling name	write in cancer name and #	_ 00 <1 year old
	98 DK (F208)	(see list above)	98 DK (F202)
14	F213	F214	F215
	1 Yes		enter age
	2 No [Nxt Sec] sibling name	write in cancer name and #	— 00 <1 year old
	98 DK (Nyt Sec)	(see list shove)	98 DK (F216)

Interviewer: write the total number of siblings here:

Cancer Types	
1. Skin (not melanoma)	12. Melanoma
2. Lung	13. Oral cavity
3. Breast	14. Ovary
4. Colon	15. Pancreas
5. Prostate	16. Rectum
6. Bladder	17. Stomach
7. Brain	18. Uterine (corpus uteri)
8. Cervix	19. Other cancer (specify)
9. Kidney	20. Cancer of female reproductive organs; site unknown
10. Leukemia	21. Cancer of the large bowel(colon/rectum) site unknown
11 Lymphoma	22. Relative had cancer site; unknown

		- 	
	Did (first name) have any other cancer?	What was the second type of cancer (NAME) had?	How old was (HE/SHE) when this cancer was diagnosed?
8	F132 1	F133	F134 enter age
	2 No (F138) sibling name 98 DK (F138)	write in cancer name and # (see list above)	00 < 1 year old 98 DK (F135)
9	F146 1	F147	F148 enter age
	2 No (F152) sibling name 98 DK (F152)	write in cancer name and # (see list above)	00 < 1 year old 98 DK (F149)
10	F160 1 Yes	F161	F162 enter age
	2 No (F166) sibling name 98 DK (F166)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F163)
11	F174 1	F175	F176 enter age
	2 No (F180) sibling name 98 DK (F180)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F177)
12	F188	F189	F190 enter age
	2 No (F194) sibling name 98 DK (F194)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F191)
13	F202 1 Yes	F203	F204 enter age
	2 No (F208) sibling name 98 DK (F208)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F205)
14	F216 1 Yes	F217	F218 enter age
	2 No [Nxt Sec] sibling name 98 DK [Nxt Sec]	write in cancer name and # (see list above)	00 <1 year old 98 DK (F219)

Interviewer: write the total number of siblings here: ______.

Can	cer	Typ	es

1. Skin (not melanoma)	12. Melanoma
2. Lung	13. Oral cavity
3. Breast	14. Ovary
4. Colon	15. Pancreas
5. Prostate	16. Rectum
6. Bladder	17. Stomach
7. Brain	18. Uterine (corpus uteri)
8. Cervix	19. Other cancer (specify)
9. Kidney	20. Cancer of female reproductive organs; site unknown
10. Leukemia	21. Cancer of the large bowel(colon/rectum site unknown
11. Lymphoma	22. Relative had cancer; site unknown

	Did (first name) have any other	What was the third type of	How old was (HE/SHE)
	cancer?	cancer (NAME) had?	when this cancer was
			diagnosed?
8	F135	F136	F137
	1 Yes		enter age
	2 No (F138) sibling name	write in cancer name and #	00 <1 year old
	98□DK (F138)	(see list above)	98 DK (F138)
9	F149	F150	F151
	1 Yes		enter age
l	2 No (F152) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F152)	(see list above)	98 DK (F152)
10	F163	F164	F165
	1 Yes		enter age
	2 ☐No (F166) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F166)	(see list above)	98 DK (F166)
11	F177	F178	F179
	1 Yes		enter age
	2 No (F180) sibling name	write in cancer name and #	00 <1 year old
	98 DK (F180)	(see list above)	98 DK (F180)
12	F191	F192	F193
	1 Yes		enter age
	2 No (F194) sibling name	write in cancer name and #	00 <u></u> <1 year old
1	98 DK (F194)	(see list above)	98 DK (F194)
13	F205	F206	F207
1	1 Yes		enter age
	2 No (F208) sibling name	write in cancer name and #	00
	98 DK (F208)	(see list above)	98 DK (F208)
14	F219	F220	F221
1	1 Yes		enter age
	2 No [Nxt Sec] sibling name	write in cancer name and #	00 <u> </u>
	98 DK [Nxt Sec]	(see list above)	98 DK (F222)

Interviewer: write the total number of siblings here: _____.

Interviewer: enter total number of children

I would like to ask you the same questions about your children. Again, include those who are living or deceased, but do not include adopted, foster, or step children.

How many children do y please include any who r				F222
hranna marana and		# Natura	ıl Children	
		00 None		
		98 DK		
		99 🗆 R		
\longrightarrow (Ge	to next section)	/ <u> </u>		
Interviewers please list all	=	in first column the	n go back to first chi	ild and complete
information across a row.		•		www.www.grana
What is the first name of	What is	Is (name) still	How old is	How old was
your (oldest/next) Child?	(name's) sex?	living?	(name) ?	(name) when
your (ordess now, ourse,	(Manie 5, 55		(11111)	(he/she) died?
F223 oldest	F224	F225	F226	F227
name	l Male	1 Yes	enter age	enter age
98 DK (F224)	2 Female	2 No (F227)		00 <1 year old
99 R	98∐ DK	98 DK (F228)	98 DK (F228)	98 DK (F228)
		<u> </u>		
F234	F235	F236	F237	F238
name	1 Male	1 Yes	enter age	enter age
00 No more children	2 Female	2 No (F238)		00 <u></u> <1 year old
98 DK (F235)	98□ DK	98 DK (F239)	98 DK (F239)	98 DK (F239)
F245	F246	F247	F248	F249
name	1 Male	1 Yes	enter age	enter age
00 No more children	2 Female	2 No (F249)	00 DY (E260)	00 < 1 year old
98 DK (F246)	98 DK	98 DK (F250)	98 DK (F250)	98 DK (F250)
F256	F257	F258	F259	F260
name 00 No more children	1 Male	l Yes	enter age	enter age 00 <1 year old
	2 Female 98 DK	2 No (F260) 98 DK (F261)	98 DK (F261)	98 DK (F261)
98 DK (F257) F267	98 DK F268	F269	F270	F271
name	1 Male	l Yes	enter age	enter age
00 No more children	2 Female	2 No (F271)		00 < 1 year old
98 DK (F268)	98 DK	98 DK (F272)	98 DK (F272)	98 DK (F272)
F278	F279	F280	F281	F282
name	1 Male	1 Yes	enter age	enter age
00 No more children	2 Female	2 No (F282)		00 <1 year old
98 DK (F279)	98∐ DK	98 DK (F283)	98 DK (F283)	98 DK (F238)
F289	F290	F291	F292	F293
name	1 Male	l Yes	enter age	enter age
00 No more children	2 Female	2 No (F293)		00 <1 year old
98 DK (F290)	98 <u></u> DK	98 DK (F294)	98 DK (F294)	98 DK (F294)
		_ · · ·		

11. Lymphoma

Interviewer: enter total # of children

Cancer Types	
1. Skin (not melanoma)	12. Melanoma
2. Lung	13. Oral cavity
3. Breast	14. Ovary
4. Colon	15. Pancreas
5. Prostate	16. Rectum
6. Bladder	17. Stomach
7. Brain	18. Uterine (corpus uteri)
8. Cervix	19. Other cancer (specify)
9. Kidney	Cancer of female reproductive organs; site unknown
10. Leukemia	 Cancer of the large bowel(colon/rectum); site unknown

22. Relative had cancer; site unknown

How old was (HE/SHE) What was the first type of Was (first name) ever when this cancer was cancer (NAME) had? diagnosed as having any type diagnosed? of cancer? F230 F229 F228 1 enter age 1 Yes 00 <1 year old 2 No (F234) child's name write in cancer name and # 98 DK (F231) 98 DK (F234) (see list above) F241 F240 F239 2 enter age 1 Yes_ <1 year old 00 2 No (F245) child's name write in cancer name and # 98 DK (F242) 98 DK (F245) (see list above) F252 F251 F250 3 enter age 1 Yes 00 <1 year old 2 No (F256) child's name write in cancer name and # 98 DK (F253) 98 DK (F256) (see list above) F263 F262 F261 4 enter age 1 Yes <1 year old child's name 2∏No (F267) write in cancer name and # 98 DK (F264) 98 DK (F267) (see list above) F274 F273 F272 5 enter age 1 Yes_ 00 < 1 year old write in cancer name and # 2 No (F278) child's name 98 DK (F275) 98 DK (F278) (see list above) F285 F284 6 F283 enter age 1 Yes <1 year old 2 No (F289) child's name write in cancer name and # 98 DK (F286) 98 DK (F289) (see list above) F296 F295 F294 enter age 1 Yes 00 <1 year old 2 No [NxtSec] child's name write in cancer name and # 98 DK (F297) 98 DK [Nxt Sec] (see list above)

Interviewer: enter total number of children

Cancer Types			
1. Skin (not	: melanoma)	12.	Melanoma
2. Lung		13.	Oral cavity
3. Breast		14.	Ovary
4. Colon		15.	Pancreas
5. Prostate		16.	Rectum
6. Bladder		17.	Stomach
7. Brain		18.	Uterine (corpus uteri)
8. Cervix		19.	Other cancer (specify)
9. Kidney		20.	Cancer of female reproductive organs; site unknown
10. Leukemi	a	21.	Cancer of the large bowel(colon/rectum); site unknown
11. Lymphor	ma	22.	Relative had cancer; site unknown

	Did (first name) have a second cancer?	What was the second type of cancer (NAME) had?	How old was (HE/SHE) when this cancer was diagnosed?
1	F231 1 Yes	F232	F233 enter age 00 < 1 year old
	2 No (F234) child's name 98 DK (F234)	write in cancer name and # (see list above)	98 DK (F234)
2	F242 1 Yes	F243	F244 enter age
	2 No (F245) child's name 98 DK (F245)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F245)
3	F253 1 Yes	F254	F255 enter age
	2 No (F256) child's name 98 DK (F256)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F256)
4	F264 1 Yes	F265	F266 enter age
	2 No (F267) child's name 98 DK (F267)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F267)
5	F275 1 ☐ Yes	F276	F277 enter age
	2 No (F278) child's name 98 DK (F278)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F278)
6	F286 1 Yes	F287	F288 enter age
	2 No (F289) child's name 98 DK (F289)	write in cancer name and # (see list above)	00 <1 year old 98 DK (F289)
7	F297	F298	F299 enter age
	1 Yes	write in cancer name and # (see list above)	00

	What is the first name of	What is	Is (name) still	How old is	How old was
	your (oldest/next) Child?	(names) sex?	living?	(name) ?	(name) when
					(he/she) died?
8	F300	F301	F302	F303	F304
	name	1 Male	l Yes	enter age	enter age
	00 None [Nxt Sec]	2 Female	2 No (F304)		00 <1 year old
	98 DK (F301)	98□ DK	98 DK (F305)	98 DK (F305)	98 DK (F305)
9	F311	F312	F313	F314	F315
	name	l Male	l Yes	enter age	enter age
	00 None [Nxt Sec]	2 Female	2 No (F315)		00 <1 year old
	98 DK (F312)	98[] DK	98 DK (F316)	98 DK (F316)	98 DK (F316)
10	F322	F323	F324	F325	F326
	name	1 Male	l Yes	enter age	enter age
	00 None [Nxt Sec]	2 Female	2 No (F326)		00 <1 year old
	98 DK (F323)	98 DK	98 DK (F327)	98 DK (F327)	98 DK (F327)
		_			
11	F333	F334	F335	F336	F337
1	name	1 Male	l Yes	enter age	enter age
	00 None [Nxt Sec]	2 Female	2 No (F337)		00 <1 year old
l	98 DK (F334)	98 DK	98 DK (F338)	98 DK (F338)	98 DK (F338)
12	F344	F345	F346	F347	F348
	name	1 Male	l Yes	enter age	enter age
	00 None [Nxt Sec]	2 Female	2 No (F348)		00 <1 year old
	98 DK (F345)	98 DK	98 DK (F349)	98 DK (F349)	98 DK (F349)
13	F355	F356	F357	F358	F359
	name	1 Male	l Yes	enter age	enter age
	00 None [Nxt Sec]	2 Female	2 No (F359)	l <u>_</u>	00 <1 year old
	98 DK (F356)	98 DK	98 DK (F360)	98 DK (F360)	98 DK (F360)
14	F366	F367	F368	F369	F370
	name	l Male	1 Yes	enter age	enter age
ł	00 None [Nxt Sec]	2 Female	2 No (F370)		00 <1 year old
l	98 DK (F367)	98∐ DK	98 DK (F371)	98 DK (F371)	98 DK (F371)

Interviewer: Enter total number of children_

Women's Questionnaire

Let us begin this section of questions by relating them to specific periods of your life. To help you become oriented to that period of time in your life think about where you were living, what your job was at the time, if you were married.

1.	What was your weight two years ago? (code directly to nearest pound)	1-500lbs. 98	1
2.	What was your weight ten years ago? (code directly to nearest pound)	1-500lbs. 98	2
3.	What was your weight twenty years ago? (code directly to nearest pound)	98 DK 99 R	3
4.	What was your weight at age 16? (code directly to nearest pound)	1-500lbs. 98	4
5.	What was your height two years ago?	ftin	5
6.	Approximately how old were you when you had your first menstrual period?	1-96y.o. 98	6
7.	At what age did you have your last perio	od? 1-96y.o. 2 still has 98 DK 99 R	7
ı	→ If "still has periods", go to Q9		8
8.	Why did your periods stop?	1 Menopause 2 Hysterectomy 3 Chemotherapy, X-Ray, 4 Pills 5 Other 98 DK 99 R	
	If "Other", specify:		

9. Have you ever had an ovary removed?	Yes (bilat)* - No Yes, (unilat)* DK R	☐ 1 ☐ 2 ☐ 3 ☐ 98 ☐ 99	9
If "No", go to Q11 * bilat=bilateral, both sides; unilat=unilateral, one si		□ 99	
10. What age were you when your ovary (is was (were) removed?	es)? 1-97y.o. DK		10
11. Did you ever have any problems with y breasts, such as lumps, cysts, and/or fib			11
If "No", go to Q17			
12. Was this diagnosed by a physician? If "No", go to Q17	Yes		12
13. Did the doctor do a biopsy of your brea when you had this problem?	ust Yes		13
☐ If "No", go to Q 17			
14. Please tell me the name and address of which it was done. (DK=98, R=99)	the hospital/clinic when	e this was done and t	he year in
Hospital/Clinic name City/State	141516		
Vear highest performed			

This section of the interview concerns your pregnancy history.

17. Have you ever been pregnant?	Yes 1	17
<u></u>	——— No 🔲 2	<u> </u>
·	DK 🗍 98	
	. R 🗍 99	
☐ If "No", go to Q19		.

18. Please answer the following questions about each of your pregnancies including those that did not result in a live birth.

	A	В	С	D	E	F	G	H
did y beco	t age rou me nant? OK	What was the outcome? 1=live birth 2=stillbirth 3=miscarriage 4=abortion 5=tubal pregnancy 8=DK 9=R (if "3,4, or 5, go to next pregnancy)	How many wks did you carry this baby? 98=DK 99=R	What was the baby's sex? 1=male 2=female 98=DK 99=R (stillborn go to H)	Did you breast feed this baby? 1=No 2=Yes 8=DK 9=R (if No go to H)	For how many months? 98=DK 99=R	Why did you stop nursing? 1=normal weaning 2=cracked nipples 3=painful 4=little milk 5=other med 6=other nonmedical 98=DK 99=R	Did you take a shot or pill to dry up your milk? 1=Yes shot 2=No 3=Yes pills 4=Yes, DK shot or pill 98=DK 99=R
	AGE	OUTCOME	WEEKS	SEX	NURSED	Months	STOPPED	DRY UP?
1								
2								
3								
4								
5								
6								
7								
8								
9								
10								

"Now I have some questions about the use of hormone medications. The first questions are about hormone replacement therapy, hormones that are taken around the time of menopause. This does not include hormones used for birth control."

Hormone Replacement Therapy (HRT)

Interviewer:	show card F							
19. Did you	ever take any type of estrogen, s	uch as Pren	narin, progesterone,					
	such a Provera, testosterone, and other hormone medication (Show Card):							
1) meno	1) menopause-related symptoms (hot flashes, sweating, vaginal dryness, bladder problems)							
2) depre	2) depression, anxiety, emotional distress							
	cement therapy after hysterecton							
	porosis (bone loss), to prevent of							
5) cardio	ovascular disease, to prevent care	diovascular	disease					
	ılar menstrual periods, to regulat							
7) treatn	ment of disease (specify)					
8) preve	ention of disease (specifyestrogen effect in a woman using)					
		g menopaus	sal estrogens					
98) other	(specify)					
7	ormones could include pills, vag Yes		s or suppositories, injections, or skin patches. 10", go to Q24					
20. Were the	ese hormones (estrogen, progeste	erone, or te	stosterone)					
in the for	rm of a:							
A. P	Pill	Yes 1	l					
в. \	Vaginal Cream or Suppository	Yes 1	No _ 2					
	Skin Patch	Yes 🔲 1	No 2					
D. S	Shot	Yes 1	No _ 2					
21. When yo	ou were taking these (hormones)	, did you ta	ke them for 3 straight months or more?					
A. F	Pill	Yes 🔲 1	No					
в. У	Vaginal Cream or Suppository	Yes 1	No \square 2 (yes \rightarrow Complete 23.1-23.12)					
c. S	Skin Patch	Yes 1	No					
D. S			No					
If "I	No", go to Q24	•						

"Now I would like to ask you some details about your use of these hormones. First, see if you can recognize the specific type(s) you used from this chart." [show examples]

22. If Estrogen, Progesterone, or Testosterone Pills Reported

Complete 22.1-22.12 for each episode of use.

22.	.1-22.2	22.3	22.4-22.5	22.6	22.7
What is the	he name of the t) pill you took?	Please tell me the reason you used this	At what age did you (first/next) start taking this pill?	How many total years and months between	When you were taking this hormone between (ages in 22.4
code. Pro	nplete name and obe for frequency of measure.	pill?	At what age did you stop taking this pill?	(ages in 22.4 and 22.5) did you take this pill?	and 22.5) did you usually take it every day, or in cycles?
[show ex	amples]	[show card]	If still taking, record current age.		
1st	Name: Code: per 1day	(specify reason)	Age start	Years #of and	Every day
Pill	#pills 2week	code:	Age stop	Months	Other (specify)8
2nd Pill	Name:	(specify reason)	Age start	Years #of and	Every day4 Every other day5 In Cycles (specify)7
	#pills 2week	code:	Age stop	Months	Other (specify)8
3rd	Name:	(specify reason)	Age start	Years #of and	Every day4 Every other day5 In Cycles (specify)7
Pill	per 1day #pills 2week	code:	Age stop	Months	Other (specify)8
4th	Name:	(specify reason)	Age start	Years #of and	Every day4 Every other day5 In Cycles (specify)7
Pill	per 1day #pills 2week	code:	Age stop	#of Months	Other (specify)8

If hormone was estrogen, go to Q22.8. If not, go to 23.1.

22.	8	While '	vou	were	taking	estrogen	pills,	did	vou also	take	progesterone?
	_		,				P,		,		broken outer

Yes 1	No	Go to next hormone

22.9-22.10

22.11-22.12

What is the name of the	During the (first/next) time when you were taking (estrogen) and (progesterone) in the						
progesterone that you			i you usually take	the estrogen and on which days did you			
took with this estrogen?		e progesterone?					
Enter complete name and	Circle first	and last dates of	each. Then conn	ect first to last with a line. Enter the Start			
code. Probe for	Day and End D	Day for Estrogen	(E) and Progeste	rone (P) and record total number days on			
frequency and unit of	Estrogen (E), F	Progesterone (P)	and Estrogen plu	us Progesterone (E+P).			
measure.							
[show examples]	1234567	8 9 10 11 12	13 14 15 16 17	18 19 20 21 22 23 24 25 26 27 28 29 30 31			
	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEE			
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPP PPP PPPP			
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone			
				between (ages in 22.4 and 22.5), how often did			
per 1Day	E P	E P	E P	you take it?			
#Pills 2Week				9Every month 11Every 3 rd month			
			E+P	9Every month 11Every 3 rd month 10Every other month 12Every 4 th month			
			E+P	8Other (Specify)			
	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEE			
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPPPPPPPP			
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone			
				between (ages in 22.4 and 22.5), how often did			
per 1Day	E P	E P	E P	you take it?			
#Pills 2Week				9Every month 11Every 3 rd month			
			E+P	10Every other month 12Every 4th month			
				8Other (Specify)			
	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEE			
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPP PPPPPPPP			
	Start Davi	Stan Davi	Total Davis	When you were taking this progestorone			
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone between (ages in 22.4 and 22.5), how often did			
		l <u></u> -		you take it?			
per 1Day	E P	E P	E P	'			
#Pills 2Week				9Every month 11Every 3 rd month			
		:	E+P	10Every other month 12Every 4 th month			
	CECCEC			8Other (Specify)			
	EEEEEEE P PPPPP P	EEEE E PPPPP					
Name:	FFFFFF	****					
Cada	Start Day	Stop Day	Total Days	When you were taking this progesterone			
Code:		Stop Duy	10121 24/5	between (ages in 22.4 and 22.5), how often did			
nes 1 Devi	E P	E P	E P	you take it?			
per 1Day	E F	E P	E P	l			
#Pills 2Week				9Every month 11Every 3 rd month			
			E+P	10Every other month 12Every 4 th month 8Other (Specify)			
	EEEEEEE	EEEEE	EEEEE	E E E E E E E E E E E E E			
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPP PPPPPPPP			
1141110							
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone			
				between (ages in 22.4 and 22.5), how often did			
per 1Day	E P	E P	E P	you take it?			
#Pills 2Week				9Every month 11Every 3 rd month			
1110 2 17 OUR			E+P	9Every month 11Every 3 rd month 10Every other month 12Every 4 th month			
			E ⁺ F	8Other (Specify)			

23. If Vaginal Cream or Suppository Reported:

Complete 23.1-23.12

23	.1-23.2	23.3	23.4-23.5	23.6	23.6a	23.7
What is t	he name of the	Please tell me	At what age did	How many	If using	When you were
	t) vaginal cream	the reason	you (first/next)	total years	cream, how	taking this
	sitory you used?	you used this	start taking this	and months	many	hormone between
or suppo.	sitory you used.	vaginal cream	vaginal cream or	between	applicator-	(ages in 23.4 and
F-4	mplete name and	or	suppository?	(ages in 23.4	fulls did	235) did you
	obe for frequency	suppository?	At what age did	& 23.5) did	you use	usually take it
		suppository:	you stop?	you use this	each time	every week, or in
and unit	of measure.			cream or	cacii tiiiic	cycles?
١			If still using,			cycles:
[show ex	amples	[show card]	record current	suppository?		
			age.		25	F
1		(specify reason)		Years #of	.251 .502	Every week6
1 1	Name:		A con start	#of rears	1.03	In Cycles(specify)7
1 1	Cada		Age start	#01	1.54	in Cycles(specify)7
ıst	Code: per 1day			and	2 or more5	
Crm/	#times 2week		Age stop		Unknown9	
Supp	3month	code:		Months		Other (specify)8
''	4year		•	#of		
1						
		(specify reason)		-	.251	Every week6
	Name:			Years	.502	
			Age	#of	1.03	In Cycles(specify)7
2nd	Code:		start		1.54 2 or more5	
Crm/	per 1day			and	Unknown9	
Supp	#times 2week 3month	code:	Age	Months	Olikilowii9	Other (specify)8
Jupp	3monun 4year	code:	stop	#of		Outer (specify)
	4ycai		, 3.0p			
-		(specify reason)			.251	Every week6
1	Name:	``		Years	.502	
			Age	#of	1.03	In Cycles(specify)7
3rd	Code:		start	<u> </u>	1.54	
Crm/	per 1day			and	2 or more5	
Supp	#times 2week	·		Months	Unknown9	Other (specify)8
Supp	3month	code:	stop	#of		Outer (specity)
	4year		stop	"01		
		(specify reason)			.251	Every week6
	Name:	```		Years	.502	
			Age	#of	1.03	In Cycles(specify)7
4th	Code:		start		1.54	
Crm/	per 1day	l ———		and	2 or more5	
	#times 2week	1 .) / a mah =	Unknown9	Other (specify)8
Supp	3month	code:	Age	Months		Other (specify)
	4year		stop	#of		·
		(specify reason)			.251	Every week6
	Name:	(specify reason)		Years	.502	
	ITALIRE.		Age	#of	1.03	In Cycles(specify)7
1	Code:		start		1.54	
5th	per 1day		1	and	2 or more5	
Crm/	#times 2week		1		Unknown9	1
Supp	3month	code:	Age	Months		Other (specify)8
1	4year		stop	#of		
ł	1	I	1	1	1	l

If hormone was estrogen, go to Q23.8. If not, go to 24.

23.8	While you were	using estrogen	(cream/supposito	ry), did you al:	so take progesterone?
------	----------------	----------------	------------------	------------------	-----------------------

•	Yes 1 No 2 — Go to next hormone	
3.10	23.11-23.12	

23.9-23.10		+ ;	23.11-23.12	•		
What is the name of the	During the	(first/next) time	when you were ta	king (estrogen) and (progesterone) in the		
progesterone that you			i you usually take	the estrogen and on which days did you		
took with this estrogen?		e progesterone?				
Enter complete name and				ect first to last with a line. Enter the Start		
code. Probe for				rone (P) and record total number days on		
frequency and unit of	Estrogen (E), F	Progesterone (P)	, and Estrogen pli	is Progesterone (E+P). ~		
measure.						
[show examples]	1234567	89101112	13 14 15 16 17	18 19 20 21 22 23 24 25 26 27 28 29 30 31		
	EEEEEEE P PPPPP P	EEEEE E PPP P P	E E E E E P P P P P			
Name:						
Cada	Start Day	Stop Day	Total Days	When you were taking this progesterone		
Code:	J 2,	crop 2 try		between (ages in 23.4 and 23.5), how often did		
non 1 Dour	E P	E P	E P	you take it?		
per 1Day #Pills 2Week	E r	ני נ	L r			
#F1115 2 WCCK			<u> </u>	9Every month 11Every 3 rd month 10Every other month 12Every 4 th month		
			E+P	8Other (Specify)		
	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEE		
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPP PPPPPPPPPPPPPPPPPPPPPPPPPPPPPPP		
				119		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone between (ages in 23.4 and 23.5), how often did		
				you take it?		
per 1Day	E P	E P	E P	•		
#Pills 2Week	1			9Every month 11Every 3 rd month		
			E+P	10Every other month 12Every 4 th month 8Other (Specify)		
	EEEEEEE	EEEEE	EEEEE	E E E E E E E E E E E E E		
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPPPPPPPPP		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone		
				between (ages in 23.4 and 23.5), how often did you take it?		
per 1Day	E P	E P	E P	you take it.		
#Pills 2Week				9Every month 11Every 3 rd month		
·			E+P	10Every other month 12Every 4th month		
	FFFFFF		EEEEE	8Other (Specify)		
Name	EEEEEEE P PPPPP P	EEEEE E PPPPP				
Name:		• • • • •	• • • • •	• • • • • • • • • • • • • • • • • • •		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone		
				between (ages in 23.4 and 23.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week				9Every month 11Every 3 rd month		
			E+P	10Every other month 12Every 4th month		
				8Other (Specify)		
	EEEEEEE	EEEE E PPP P P	E E E E E P P P P P	EEEEEEEEEEE		
Name:	PPPPPPP	PPPPP	rrrr	PPPPPP PPPPPPPPPPPPPPPPPPPPPPPPPPPPPPP		
0-4	Start Day	Stop Day	Total Days	When you were taking this progesterone		
Code:	June Day	otop Day	Tomi Days	between (ages in 23.4 and 23.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week			~ 1	9Every month 11Every 3 rd month		
1113 2 WOOR			E+P	10Every month 11Every 3 th month		
			E-F	8Other (Specify)		
		·	<u> </u>			

24. If Hormone Skin Patches Reported:

Complete 24.1-24.12 for each episode of use.

24.1-24.2		24.3	24.4-24.5	24.6	24.7
What is the name of the		Please tell me	At what age did you	How many total	When you were
(first/next) hormone skin		the reason	(first/next) start using	years and	using these skin
patch you used?		you used this	these patches?	months between	patches between
paten you	a asea.	skin patch?	•	(ages in 24.4	(ages in 24.4 and
Enter co	mplete name and	Skiii pateiii	At what age did you stop?	and 24.5) did	24.5) did you usually
	obe for frequency		in manage and years are	you take these	take it every week or
	of measure.		If still taking, record	skin patches?	in cycles?
and unit	of fileasure.	·	current age.	J P	
		[show card]	Current age.		
[show ex	ampiesj	(specify reason)			Every week6
	Name:	(specify reason)		Years	In Cycles (specify)7
	ivanic.		Age start	#of	in Cycles (speein)
ıst	Code:		Age start	and	
Patch	per 1day	1		and	Other (specify)8
Used	#times 2week	ļ 	· Agastan	Months	Outer (speeny)
ļ	3month		Age stop	#of	
	4усаг	code:		#01	
		(specify reason)	·		Every week6
	Name:		i	Years	In Cycles (specify)7
2nd	0.4.		Age start	#of	
Patch	Code:			and	
Used	#times 2week		•		Other (specify)8
	3month	Ì	Age stop	Months	
	4year	code:		#of	
		(specify reason)			Every week6
	Name:			Years	In Cycles (specify)7
3rd			Age start	#of	
Patch	Code:			and	
Used	per 1day				Other (specify)8
0.00	#times 2week 3month		Age stop	Months	
l .	4year	code:		#of	
	7, 5-41	(specify reason)			Every week6
	Name:	, , , , , , , , , , , , , , , , , , , ,		Years	In Cycles (specify)7
ļ		•	Age start	#of	' ' '
4th	Code:			and	
Patch	per 1day				Other (specify)8
	#times 2week		_Age stop	Months	
Used	3month	code:		#of	
	4year				Every week6
1	Name	(specify reason)		Years	In Cycles (specify)7
	Name:	1	A	#of	In Cycles (specity)/
5th	Code:		Age start		
Patch	per 1day			and	Other (specify)8
Used	#times 2week		A	Months	Outer (specity)0
1	3month	1	Age stop	#of	
ł	4vear	code:	1	#OI	

If hormone was estrogen, go to Q24.8. If not, go to 25.

24.9-24.10

24.8 While you were using estrogen skin patches, did you also take progesterone?

Yes 🔲 1	No [2	Go to next hormone
. ₩	24.11-24.12	

What is the name of the	During the (first/next) time when you were taking (estrogen) and (progesterone) in the						
progesterone that you	same month, on which days did you usually take the estrogen and on which days did you						
took with this estrogen?	usually take th						
Enter complete name and	Circle first and last dates of each. Then connect first to last with a line. Enter the Start						
code. Probe for							
frequency and unit of		Day and End Day for Estrogen (E) and Progesterone (P) and record total number days on Estrogen (E), Progesterone (P), and Estrogen plus Progesterone (E+P).					
measure.	251108011 (2), 1	Estrogen (E), 1 rogesterone (1), and Estrogen plus 1 rogesterone (E+1).					
[show examples]	1234567	8 9 10 11 12	13 14 15 16 17	18 19 20 21 22 23 24 25 26 27 28 29 30 31			
	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEEE			
Name:	PPPPPPP	PPPPP	PPPPP				
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone between (ages in 24.4 and 24.5), how often did			
				you take it?			
per 1Day	E P	E P	E P	you take it:			
#Pills 2Week				9Every month 11Every 3 rd month			
			E+P	10Every other month 12Every 4th month			
i	İ		D.1	8Other (Specify)			
	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEE			
Name:	PPPPPP	PPPPP	PPPPP	PPPPP PPP PPPP			
Trumo.	1						
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone			
	1	. ,	•	between (ages in 24.4 and 24.5), how often did			
per 1Day	E P	E P	E P	you take it?			
#Pills 2Week	- '	L 1	L 1	1 5 5 3 1 5 3 1 5 1			
#FIIIS 2 WEEK				9Every month 11Every 3 rd month 10Every other month 12Every 4 th month			
E+P 10Every other mon 8Other (Specify)							
	EEEEEEE	EEEEE	EEEEE	E E E E E E E E E E E E E			
N	PPPPPPP	PPPPP		PPPPPP PPPPPPPP			
Name:	1						
l _a ,	Start Day	Stop Day	Total Days	When you were taking this progesterone			
Code:) Sunt Duy	Otop Day	10mi Duys	between (ages in 22.4 and 22.5), how often did			
	E P	E P	E P	you take it?			
per 1Day	E P	E P	E P				
#Pills 2Week				9Every month 11Every 3 rd month			
i		ļ	E+P	10Every other month 12Every 4th month			
				8Other (Specify)			
l	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEE			
Name:	PPPPPPP	PPPPP	PPPPP	PPPPPP PPPPPPPPPPPPPPPPPPPPPPPPPPPPPPP			
'	Ctord David	Stan Barr	Total Danie	When you were taking this progesterone			
Code:	Start Day	Stop Day	Total Days	between (ages in 24.4 and 24.5), how often did			
				you take it?			
per 1Day	E P	E P	E P	, v			
#Pills 2Week				9Every month 11Every 3 rd month			
		I	E+P	10Every other month 12Every 4th month			
				8Other (Specify)			
·	EEEEEEE	EEEEE	EEEEE	EEEEEEEEEEEE			
Name:	PPPPPPP	PPPPP	PPPPP				
		1					
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone			
		-		between (ages in 24.4 and 24.5), how often did			
per 1Day	E P	E P	E P	you take it?			
#Pills 2Week] ~ `	- •		0 F			
#1'1115 2 W CCR			F-5	9Every month 11Every 3 rd month 10Every other month 12Every 4 th month			
		1	E+P				
L	<u> </u>	<u> </u>	L	8Other (Specify)			

25. If Estrogen, Progesterone, or Testosterone Shots Reported:

Complete 25.1-25.12

	25.1-25.2	25.3	25.4-25.5	25.6	25.7
What is the name of the		Please tell me	At what age did you	How many total	When you were
(first/next) hormone shot		the reason	(first/next) start receiving	years and	receiving these
you received?		you received	this hormone shot?	months between	hormone shots
you received:		this shot?		(ages in 25.4	between (ages in 25.4
Enter co	mplete name and	11110 011011	At what age did you stop?	and 25.5) did	and 25.5) did you
	robe for frequency	į į	716 William #80 C ,	you receive	receive them every
	of measure.		If still taking, record	these hormone	month or in cycles?
and unit	of incasure.	!	current age.	shots?	
Ichow ex	kamples]	[show card]	Carron apr		
[SHOW OF	Т	(specify reason)			Every week6
ĺ	Name:	(3000, 10		Years	Every month7
1st	Name.	[Age start	#of	In Cycles (specify)9
Shot	Code:			and	III OJ 4140 (opozinjimi
2000	per Week2	į		LM	
	#Times Month3		Age stop	Months	Other (specify)8
	Year4	code:		#of	Omit: (2 F 22-2),
	1 041	(specify reason)			Every week6
	Name:	(4)		Years	Every month7
2nd	I Name.		_Age start	#of	In Cycles (specify)9
Shot	Code:			and	,
31101	per Week2				
	#Times Month3		Age stop	Months	Other (specify)8
	Year4	code:		#of	
		(specify reason)			Every week6
	Name:			Years	Every month7
3rd			Age start	#of	In Cycles (specify)9
Shot	Code:			and	
0	per Week2	l			
	#Times Month3		Age stop	Months	Other (specify)8
]	Year4	code:		#of	
		(specify reason)			Every week6
	Name:			Years	Every month7
			Age start	#of	In Cycles (specify)9
4th	Code:			and	
Shot	per Week2		·		
	#Times Month3		Age stop	Months	Other (specify)8
	Year4	code:		#of	
		(specify reason)			Every week6
}	Name:	``	1	Years	Every month7
5th			Age start	#of	In Cycles (specify)9
Shot	Code:			and	
0	per Week2	l	ŀ		
	#Times Month3		Age stop	Months	Other (specify)8
1	Vegr 4	code:		#of	

If hormone was estrogen, go to Q25.8. If not, go to next hormone.

25.8 While you were taking estrogen shots, did you also take progesterone?

Yes 1 No 2 Go to next hormone

25.9-25.10	25.11-25.12					
What is the name of the progesterone that you	During the (first/next) time when you were taking (estrogen) and (progesterone) in the					
took with this estrogen	same month, on which days did you usually take the estrogen and on which days did you usually take the progesterone?					
shot? Enter complete			each. Then conn	ect first to last with a line. Enter the Start		
name and code. Probe				rone (P) and record total number days on		
for frequency and unit of		(E), Progesterone (P), and Estrogen plus Progesterone (E+P).				
measure.						
[show examples]	1234567		13 14 15 16 17	18 19 20 21 22 23 24 25 26 27 28 29 30 31		
	EEEEEEE P P P P P P	EEEEE E PPP P P		EEEEEEEEEEE		
Name:	FFFFFF		rrrr	PPPPPP PPPPPPPPPPPPPPPPPPPPPPPPPPPPPPP		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone between (ages in 25.4 and 25.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week				9Every month 11Every 3 rd month		
		·	E+P	10Every other month 12Every 4th month 8Other (Specify)		
	EEEEEEE	EEEEE	EEEEE	E E E E E E E E E E E E		
Name:	PPPPPP	PPPPP	PPPP	PPPPPPPPPPPPPP		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone between (ages in 25.4 and 25.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week				9Every month 11Every 3 rd month		
			E+P	10Every other month 12Every 4 th month 8Other (Specify)		
	EEEEEEE	EEEEE	EEEEE	E E E E E E E E E E E E E		
Name:	PPPPPP	PPPPP	PPPP	PPPPPPPPPPPP		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone		
				between (ages in 25.4 and 25.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week		•		9Every month 11Every 3 rd month		
			E+P	10Every other month 12Every 4th month 8Other (Specify)		
	EEEEEEE	EEEEE	EEEEE	E E E E E E E E E E E E E		
Name:	PPPPPP	PPPPP	PPPPP	PPPPPP PPPPPPP		
Codo	Start Day	Stop Day	Total Days	When you were taking this progesterone		
Code:	ount Duy	Stop Day	roun Duys	between (ages in 25.4 and 25.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week				9Every month 11Every 3 rd month		
			E+P	10Every other month 12Every 4th month		
				8Other (Specify)		
Name:	EEEEEEE P PPPPP P	EEEE E PPP P P	E E E E E P P P P P	E E E E E E E E E E E E E E E E E E E		
	St. 4 D	C4	T (1 D	W/h an area was a taking this man and the same		
Code:	Start Day	Stop Day	Total Days	When you were taking this progesterone between (ages in 25.4 and 25.5), how often did		
per 1Day	E P	E P	E P	you take it?		
#Pills 2Week	2 .			9Every month 11Every 3 rd month		
			E+P	10Every month 11Every 3 th month		
			2.1	8Other (Specify)		

Now I	have some questions about the use of other types of female h	ormones.
26. Di	d you ever take birth control pills (oral contraceptives) for any re 1 NO 2 (Go to Q27)	eason?
L	26.1 At what age did you start taking birth control pills?y.o. 98 DK 99 R	26.1
	26.2 At what age did you stop taking birth control pills?y.o. 98 DK 99 R	26.2
	26.3 How many total years and months between (ages in 24.1 and 24.2) did you take birth control pills?yrs &months	26.3(enter in months)
<u> </u>	26.4 Did you use birth control pills before your first full-term pregnancy? Yes 1 No 2 Never pregnant 3 (Go to Q27)	26.4
	26.5 How many total years and months did you use birth control pills before your first full-term pregnancy?yrs &months	26.5
27.	Did you ever take DES (diethylstilbestrol)? Yes 1 No 2 (Go to Q28)	27
	27.1 At what age did you start taking DES? 1-96yrs. DK 98 R 99	27.1
	27.2 At what age did you stop taking DES? 1-96y.o. DK 98 R 99	27.2
	27.3 How many total years and months	27.3

between (ages in 25.1 and 25.2) did you take DES?

yrs & ____months

(enter in months)

28. Did you ever take shots called depo-provera (DMPA) for birth control or for any other reason?	
Yes 1 No 2 (Go to Q 29)	28
	28.1
28.1-28.2 When you were taking depo-provera shots, how often did you get a shot?	(times)
every month 1 #times 3 months 2	28.2
year 3	(frequency)
28.3 At what age did you start taking depo-provera shots?	28.3
1-96y.o. DK ☐ 98	
R 99	
28.4 At what age did you stop taking depo-provera shots?	28.4
1-96y.o. DK 98	
R ☐ 99	
28.5 How many total years and months between (ages in 26.2 and 26.3) did you take	
depo-provera shots?yrs &months	28.5
29. Have you taken any other female hormone medications that we have not discussed?	[20]
Yes 1	29
No 2 (Go to next section)	
29.1 What was the name of the hormone?	
29.2 What was the reason you took the hormone?	
29.3 Was this hormone in the form of a: A. Pill	
B. Vaginal Cream or Suppository B	29.3
C. Skin Patch	
(Go to Questions 6-9 if the hormone was used for reasons listed in Q17) That completes this interview on the use of female hormone medications.	Thank you very
much for your cooperation.	Z MARIEL J OM VOL J

BODY MEASUREMENTS

1. WEIGHTlbs.	BM1
convert to kilograms after interview is complete	
lbs. X .4536 = kg	BM2X
2. HEIGHTftin =	BM3
convert to meters and calculate BMI after interview is complete 12x ft	BM4
3. WAIST (measured at narrowest point)inin	BM5
4. HIP (measured at widest point)inin	BM6
calculate ratio after interview is complete	· · · · · · · · · · · · · · · · · · ·
5. Waist-to-Hip Ratio =	ВМ7

LIFESTYLE

These final questions are for statistical p	urposes only.	
What was the total number of persons in your household last year, including yo	ourself?	H032
	1-25 enter number of 98	of persons
If we need to contact you in the future, it is helpful to know the name of an individual outside your household who will always know your whereabouts. What is the name, address, and phone number of a close friend or relative who does not live with you?		HTX5
	Yes 1 98 DK [go to H041] 99 R [go to H041]	
THIS SECTION ENTER FULL TEXT		
Name:		
Street:		
Apt. #		
City		
State		•
Zipcode		
Telephone: ()		

What is [NAME]'s relationship to you?	1 mother 2 father 3 son 4 daughter 5 brother 6 sister 7 step daughter 98 DK 99 R	H037 8 step son 9 daughter-in-law 10 son-in-law 11 friend 0 other (specify)
Do you currently have a valid driver's li	1 Yes 2 No 98 DK 99 R	H038
Are you enrolled in Medicare?	1 Yes 2 No 98 DK 99 R	H039
This question asks about your househol income last year. Please mark the appr box on the piece of paper, place it back and return it to the interviewer.	opriate	HO40

- Interviewer please hand subject question on piece of paper in envelope. - Interviewer please obtain from subject when completed. Please mark the income category that best describes your total family income last year. Interviewer please complete after interview. less than 5,000 between 5,000 and 10,000 between 10,000 and 20,000 between 20,000 and 30,000 between 30,000 and 40,000 between 40,000 and 50,000 between 50,000 and 60,000 more than 60,000 98 DK 99[R **THNX** That completes the interview. You have been very helpful and I appreciate your time and cooperation. Complete this section after you have thanked and left the subject

minutes

(length of interview)

	INTERVIEW QUALITY	
Where was the interview conduc	ed?	I002
-	1 Respondent's Home 3 Hospital 5 Nursing Home 6 Somewhere else, specify	
Excluding yourself and the responsany other people were present interview?		
<u> </u>	0-10 Enter number	
If l	003 equals 0, go to I013.	
Were third parties present in all interview?	or part of the	
	1 all [go to I013] 3 part	
Which section: demographics		[I005]
	1 Spouse 3 Other (s) 5 Spouse and other (s) 7 No one present	
	-	

Section: occupational history			1007
,	1	Spouse Other (s) Spouse and other (s) No one present	
Section: diet history			
	1 3 5 7	Spouse Other (s) Spouse and other (s) No one present	
Section: medical history			1009
	1	Spouse Other (s) Spouse and other (s) No one present	
Section: family history			I010
	1	Spouse Other (s) Spouse and other (s) No one present	
Section: reproductive history			[I010A]
	1	Spouse Other (s) Spouse and other (s) No one present	
Section: lifestyle			I011
	1	Spouse Other (s) Spouse and other (s) No one present	-

1	77
	~~

Breast Cancer Risk Study; ver4. January 21, 1999		122
Quality of information in section: dem	ographics	<u>I012</u>
1	High Quality Generally reliable Questionable Unsatisfactory	
Quality of information in section: smol	king	I013
1	High Quality Generally reliable Questionable Unsatisfactory	
Quality of information in section: occu	Quality of information in section: occupational history	
1	High Quality Generally reliable Questionable Unsatisfactory	
Quality of information in section: diet	history	<u> </u>
1	High Quality Generally reliable Questionable Unsatisfactory	
Quality of information in section: med	lical	I016
1	High Quality Generally reliable Questionable Unsatisfactory	

Breast Cancer Risk Study; ver4. January 21, 1999 Quality of information in section: family history		I017	
1	High Quality Generally reliable Questionable Unsatisfactory		
Quality of information in section: repr	roductive history	[I018]	
1	High Quality Generally reliable Questionable Unsatisfactory		
Quality of information in section: lifest 1	tyle High Quality Generally reliable Questionable Unsatisfactory	I020	
The overall quality of this interview is:		I021	
*1 *3 5 7	High Quality Generally reliable Questionable[go to I024] Unsatisfactory [go to I024]		

The main reason for the unsatisfactory or questionable quality of information is because:	I022
Did not know enough information regarding the topic Did not want to be more specific Did not understand or speak english well Was bored or uninterested Was upset or depressed Had poor hearing or speech Was confused by frequent interruptions Was emotionally unstable (drunk etc) Was physically ill Other, specify [specify]	
Was the respondent's overall cooperation:	I023
1 very good 3 good 5 fair 7 poor	
END QUALITY SECTION	

HEALTH	HARITS	AND	DIET	OHESTI	ONNA	TRE
DEALID	HADIIS	AND	DICI	VUESTI	MILLIO	LINE

Study ID#_____

= Foods added for Mississippi Delta residents

Please answer these questions concerning your diet based on the year prior to your date of diagnosis. However, if you are a control participant, answer these questions based on the year prior to this interview.

HEALTH HA	BITS AND	DIET C	QUESTIONNA	RE
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Study ID:	#	
	TR	STRAW

This form asks you questions about your age, size, sex, schooling, things that you eat, drink and breathe, and how you season your food. These things may have to do with how healthy you are. Scientists would like to use this information to understand what makes people sick. This questionnaire will take you about 15 minutes to finish. Please answer all of the questions, either by writing in or circling answers or checking off the boxes that best describe your life. It is OK to guess if you are not sure!

Please do not mark in the shaded areas

1.Today's Date:		FI
Month Day	Year	M M D D Y Y
2. What is your birth date?	Month Day Year	$\begin{array}{ c c c c c c c c c c c c c c c c c c c$
3. How old are you today?	Woman Bay Toar	F3
	Years	
4. What is your sex?		F4
	1. Male 2. Female	
5. What is your race and ethnic background?	1. Caucasian, not Hispanic	F5
,	2. African-American, not Hispanic	
Choose the single answer that best	3. Hispanic/Latino	
describes you.	4. Native American/Aleut	
	5. Asian/Pacific Islander	
6. Please Indicate the highest grade in school that you finished:	12345	F6
	678910	
	11121314	
	151617+	
7. How tall are you?	feetinches	ins.
8. How much do you weigh?	pounds	F8 1bs.
9. Do you smoke cigarettes now?	a => Next page 1.Yes 2. No bcigarettes/day	a. b.

Study ID#_____

10 Daysin - 4b		LETT -		
10. During the past year, have you taken any vitamins or minerals?	1. Yes, regularly			
	2. No => SKIP TO question 16	·		
	2. No => SKIP TO question 16 3. Some, not regularly F12 A. Multi-Vitamins			
11. Describe the pills you take regularly:		F12 A.		
	B. Stress Tabs	В		
	C. Therapeutic (Theragran)	C		
	D. Vitamin AIU	D		
	E. Vitamin Cmg	E		
	F. Vitamin EIU	F		
	l	G		
		На		
	-	HbHc		
The state of the s	Hc. IU mg			
12. What is (are) the brand (s) of vitamins and minerals you take?	12 a	12 a		
·	12 b	12 b		
	12 c	12 c		
	3. Some, not regularly			
13. Of pills you take, please tell us		F14		
how often you take them:	A pills each	A		
(#) nills each (day 1 week 2)	Bpills each	В		
(#) pills each (day 1, week 2)	C pills each	C		
	D pills each	D		
	E pills each	E		
	F pills each	F		
	G pills each	G		
	H pills each	Н		

Study ID#______TR STRAW

	<u></u>	TR	STRAW
14. Please CIRCLE the other dietary supplements you take, like:	A. Yeast	P15	
	B. Selenium		A
	C. Zinc		c.
	D. Iron		D
	E. Beta-carotene		E
	F. Cod liver oil		F
If you take something not listed here, please write the name in the space	G. Other (s) Ga.		G
provided.	Specify	Ga	
15. How many servings of FRUIT (not counting fruit juices) do you eat per day or week?	fruit servings each day	F16	- Approximately and the
	or week		
16. How many servings of VEGETABLES (not counting salad	vegetable servings each	F17	
or potatoes,) do you eat per day or week?	day or week		

The next section is about your usual eating habits. Think back over the last year. Write down the serving sizes, and number of times you eat the foods on the following pages. If you have any questions, please ask the research interviewer to help you. The real questions start on the next page. There will be an example there to help you remember the instructions from this page. First, check the box that describes to you the amount of a food you ate. The examples below are to show you how we describe the amount of foods in this questionnaire.

	Medium Serving	Your S	Your Serving Size:		
Example foods	Example:	Small	Med	Large	
Cantaloupe (in season)	1/4 melon			<u> </u>	
Grapefruit `	1/2				
Sweet potatoes, yams	1/2 cup				
Liver	4 ounces				
Hamburger	1 patty				

Next, tell us how often you ate this food. Write a number in the box under the times you eat the food. In the example below, the person eats Cantaloupe once a week, when it is in season. She eats grapefruit two times each month, never eats liver, and eats sweet potatoes three times a year. She eats hamburger four times each week. This table will tell us how often you eat foods listed in the questionnaire:

	Day	Week	Month	Year	Never
Cantaloupe (in season)	111				
Grapefruit		2			
Sweet Potatoes, yams			3		<u> </u>
Liver					
Hamburger		4			

Study ID#_____

FRUITS and VEGETABLES	Medium	Check Your serving size.			How many times? Write the number of times, in the box that applies to you.					Please do not' mark shaded		
VEGETABLES	Serving	S	M	L L	Day	Week	Month	Year	Never	areas		
Example: Apples	One apple	<u> </u>	1 ***	1	1 Day	WCCK	2	1 Cai	INCVCI	 		
Your Responses:		I				<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u>. L</u>		
				1						F18	F19	
Apples, applesauce, pears	(1) or 1/2 cup											
Cantaloupe (in season)	1/4 medium							i	į	F20	F21	
Oranges	(1) medium									F22	F23	
Orange or grapefruit juice	6 oz. Glass									F24	F25	
Grapefruit	1/2 medium									F26	F27	
Other fruit juices, fortified fruit drinks	6 oz. Glass									F28	F29	
Baked beans, purple, croweder, backe-eyed peas, kidneys, limas, Great northern, butter beans, pintos, red beans	3/4 cup									F30	F31	
Tomatoes, tomato juice	(1) or 6 oz.									F32	F33	
Broccoli	1/2 cup									F34	F35	
Spinach	1/2 cup					,				F36	F37	
Mustard, turnip, or collard greens	1/2 cup									F38	F39	
Coleslaw, cabbage, Sauerkraut	1/2 cup									F40	F41	
Carrots or vegetable mix with carrots	1/2 cup									F42	F43	
Green salad	(1) med bowl					,				F44	F45	
Salad dressing or mayonnaise	2 tablespoons									F46	F47	
French fries or fried potatoes	3/4 cup									F48	F49	
Sweet potatoes or yams Potatoes: boiled, baked,	1/2 cup									F50 ————————————————————————————————————	F51 F53	
mashed, potato salad	(1) or 1/2 cup									, k , J &	1 44	
Okra	1/2 cup									~		
Rice	3/4 cup									F54	F55	

Study ID#_____ TR STRAW

MEATS, CASSEROLES, MAIN DISHES	Medium	Medium Your Write the number of times, in the serving size. box that applies to you.						mark	Please do not mark shaded areas		
DISILES	Serving	S	M	L	Day	Week	Month	Year	Never		
Hamburgers, cheeseburgers or meatloaf	1 medium	3	141		Day	WOOK	IVIOITUI			F56	F57
Beef steaks or roasts	4 ounces									F58	F59
Beef, chicken, or turkey	4 ounces	_	1							F60	F61
stew or pot pie w/veggies	(1) cup										
Liver, including chicken	(1) Cu p		 	1	<u> </u>					F62	F63
livers	4 ounces										
(ribs?)	2 chops or									F64	F65
Pork chops, roast	4 ounces								1		
1 Olk Chops, Toast	2 small or 1			\vdash						F66	F67
Fried chicken	large piece									***************************************	
Chicken or turkey:	2 small or 1			 						F68	F69
roasted, stewed or broiled	large piece										
Fried fish including	4 oz. Or (1)			 	-			<u> </u>		F70	F71
catfish or fish sandwiches	sandwich	1								***************************************	n, 491
	Salidwich		1	 				<u> </u>	1	F72	F73
Fish (including catfish): broiled or baked, tuna	4 ounces										
	4 Ounces		<u> </u>		 					F74	F75
Spaghetti, lasagna, other	1 000										
pasta with tomato sauce	1 cup		ļ	-		<u> </u>				F76	F77
Hot dogs, Italian or	2 dogs/(1)		·								
Polish sausages/Kielbasa	sausage	-	╁──	 				 -	 	F78	F79
Ham, lunch meats	2 slices		ļ							F80	F81
Soups: vegetable, beef,	1 medium									Fou	Lot
minestrone, tomato	bowl						L	<u> </u>	<u> </u>		
			Chec				w many t		• 41	Please do not	
BREADS, SALTY	Medium		You		Wr		umber o			1: :-	shaded
SNACKS, SPREADS	Serving	_	ving		<u></u>		at applie			areas	
	0 11 (1)	S	M	\perp L	Day	Week	Month	Year	Never	F82	F83
White bread, bagels,	2 slices, (1)										
crackers, flour tortillas	bagel, 3 crckr			 			<u> </u>	 		F84	F85
Dark bread: rye,	2 1:										
pumpernickel, wheat	2 slices		<u> </u>				<u> </u>			F86	F87
Cornbread or muffins,	1 med or 2										
tortillas, or hushpuppies	hushpuppies	<u> </u>	ļ					 	 	F88	F89
Potato chips, pretzels,											
corn chips, popcorn	2 handfulls		<u> </u>	 				 		F90	F91
Peanuts, walnuts,											
almonds or peanut butter	2 tablespoons			 	ļ					F92	F93
Margerine on bread or	2 pats or (1)									1	* ~ ~
rolls	tablespoon		ļ	<u> </u>			ļ			F94	F95
	2 pats or (1)									1,34	10 3- 2
Butter on bread or rolls	tablespoon		<u> </u>		<u> </u>		<u>L</u>		<u> </u>		

Study ID#_____ TR STRAW

BREAKFAST FOODS	Medium Serving		Check Your serving size.		W	Vrite the	How many times? Write the number of times, in the box that applies to you.				
	Beiving	S	M	L L	Day				Never	areas	
High fiber, bran or granola cereals	(1) medium bowl		IAT		Day	W CCV	IVIOIIL	П Ісаі	INEVEL	F96	F97
Fortified cereals (Product 19, Total, Most)	(1) medium bowl									F98	F99
Other cold cereals (Corn Flakes, Rice Krispies)	(1) medium bowl									F100	FIOI
Cooked Cereals or grits (creamed wheat, oatmeal)	(1) medium bowl									F102	F103
Eggs	2 eggs			<u> </u>						F104	F105
Bacon	2 slices									F106	F107
Breakfast Sausages, links or patties	2 patties or links									F108	F109
DAIRY PRODUCTS,	Medium		Chec	ır	How many times? Write in the number of times, in the					Please do not mark shaded	
BEVERAGES	Serving		ving:		<u> </u>			olies to you		areas	
C1 1 1	<u></u>	S	M	L	Day	Week	Month	h Year	Never		
Cheeses and cheese spreads	2 slices or 2 ounces									F110	F111
Whole milk and drinks made with, not on cereal	8 ounces									F112	F113
2% milk and drinks made										F114	F115
with, not on cereal 1% or non-fat milk and	8 ounces								-	F116	F117
buttermilk, drinks made with, not on cereal	8 ounces		l							-	
Regular soft drinks, including Koolaid	12 ounces									F118	F119
Beer	12 ounce can or bottle									F120	F121
Wine	(1) medium glass 8 oz?									F122	F123
Liquor: whiskey, rum, vodka, gin, liquers	(1) Shot 2 ounces?									F124	F125
Milk or cream in coffee or tea	(1) tablespoon		_							F126	F127
Sugar in coffee or tea and on breakfast cereal	2 teaspoons						-			F128	F129
Please tell us if you eat the following:		Seld	lom c	or Neve	er S	ometime	s	Often or A	Alwavs		
Skin on chicken		i								F130	
Fat on meat		1			\top					F131	
Pork fat in greens, beans or	vegetables	1								F132	
Salt with your prepared foo										F133	
Pepper with your prepared i	foods									F134	

Study ID#	<u> </u>	
•	TR	STRAW

DESSERTS and SWEETS	Medium Serving	Check Your serving size.		How many times? Write the number of times, in the box that applies to you.					Please do not mark shaded areas	
		S	M	L	Day	Week	Month	Year	Never	
Ice Cream	1 scoop									F135 F136
Cookies, doughnuts, cake, pastry	(1) piece or 3 cookies									F137 F138
Pie	(1) slice									F139 F140
Chocolate candy	(1) Bar or (1) ounce									F141 F142

Breast Study Recruiter Training Manual

Recruiter Training Manual Outline

- I. Agenda
- II. Why this study?
- III. What will you do?
- IV. How will you do it?
- V. Resources

Recruiter Training Program

Agenda
[For training 3 or more recruiters]

, 9:30-10:00 am	Introductions/Icebreaker
10:00-10:45 am	Why This Study? [Program description/goals/video]
10:45-11:00 am	What Will You Do? [Mechanics of recruitment]
11:00-11:15 am	Why men may not want to participate [Barriers & Benefits]
11:15-11:45 am	How Will You Do It? [Script for Recruitment]
11:45-12:30 pm	Lunch
12:30-1:00 pm	Role play of the script & telephone calls
1:00-1:45 pm	Practice, Forms & Reporting Information
1:45-2:00 pm	Questions & Answers/Summary

Thank you for your willingness to participate and help us with our study!

Recruiter Training Program

Agenda [For training 1-2 recruiters]

9:00-9:15 am	Introduction/Icebreaker
9:15-9:30 am	Why This Study? [Program description/goals/video]
9:30-10:00 am	What Will You Do? [Mechanics of recruitment, Barriers & Benefits]
10:00-10:30 am	How Will You Do It? [Script for Recruiter]
10:30-10:40 am	Break
10:40-11:00 am	Role Play of the script & telephone calls
11:00-11:15 am	Practice, Forms & Reporting Information
11:15-11:30 am	Questions & Answers/Summary
11:30-12:00 pm	Lunch

Thank you for your willingness to participate and help us with our study!

Why This Study?

Program Description

DESCRIPTION OF BREAST CANCER STUDY

More and more women are being diagnosed with breast cancer. One out of every eight women will develop breast cancer in her lifetime. African-American women often develop breast cancer at an early age (before age 50) and sometimes the disease is more serious than in Caucasian women. This research project is to help us understand the causes of breast cancer. What people eat and drink and other lifestyle habits could affect their health. But not everyone with similar habits will get sick. This may be because of differences in how their bodies respond to things that they eat, drink, and smoke; and medications they take. In this study, we will ask the same questions of women with breast cancer and women without cancer, who are the same age and live in the same counties. They will be asked some questions about eating, drinking, and smoking habits, their jobs, medical histories, and other behaviors which may protect against or otherwise affect disease. Answers to these questions will be compared between women with breast cancer and those without cancer.

One of the substances that people break down differently is caffeine. It is not thought that caffeine has any relation to breast cancer, but that genes that break down caffeine, also break down other substances that could affect health. Therefore, women will take one No-Doz tabletTM by mouth, drink a glass of water, (8-10 oz.) and supply a urine sample. The No-Doz TM tablet contains caffeine, which is broken down in the body and released in the urine. Blood will also be drawn, (about 2 tablespoons). This blood will be processed to measure differences in how your body deals with things you eat, drink and smoke. Just like the answers to the questions, ways in which people break things down will also be compared between women with breast cancer and those without. From this study we hope that we will be able to see what some of the causes of breast cancer may be.

BREAST CANCER STUDY

GOALS

To find out more about

- 1. Why women get cancer
- 2. Why some women have cancers that make them die sooner than other women
- 3. Why some women get the disease at young ages (less than age 50)
- 4. What things in the environment, in our diets, and in our genes affect these outcomes
- 5. Effective ways to encourage women to participate in the study

What Will You Do?

Barriers to Participation in Research Studies Benefits to Participation

Your Message to Participants:
"DIB"

Decisions, Involvement, Benefits

Counseling Guidelines

BARRIERS TO PARTICIPATION IN STUDIES AND RESEARCH

- Usually has been well-educated, middle-class
- Poverty; lack of education and health insurance extra tests
- Time and hassle from patient's perspective
- Negative personal and family attitudes
- Inadequate evidence of benefits
- Undesirable side effects of intervention
- Protocol too invasive (e.g. blood draws)
- Too much time required to participate
- Fearful about clinical research, being a "guinea pig"
- Family concerns about trials
- Does not value clinical research
- Belief that investigator is more interested in the research than in patient's well-being
- Information about the trial is too technical and too complex to be easily understood
- Problems with transportation and travel time

BENEFITS TO PARTICIPATION IN RESEARCH

- Help our daughters/granddaughters
- Knowledge offers more information

Source: Recruiting Into Clinical Trials: Toward a Participant-Friendly System. G. Marie Swanson and Amy J. Ward. Journal of National Cancer Institute., Vol. 87, No. 23, December 6, 1995.

YOUR MESSAGE TO PATIENTS

"DIB"

DECISION, INVOLVEMENT, BENEFITS

Decision

When you talk with patients, one of the areas you will discuss is why they may choose to participate in the research and what is their decision-making process.

Guidelines:

- Focus on the experience What will she consider in deciding?
- Share the important fact that influenced you Who or what things helped you decide
 that it is important to know <u>WHY</u> women get cancer?
 Why <u>YOU</u> or <u>SHE</u> got cancer.
- Share the difficulties and issues. What are the issues that may affect her decision?

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Involvement

It is important for you to share with patients and controls what is involved in the stu	dy
experience – the issues which affect her decision to participate in a study.	•

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•	Give the patient a "picture" of the experience – don't frighten them, but let them know the kinds of things involved in the study experience.
•	Help them feel informed about what to expect
Li	st some of the things that are involved in the research process:
	,

Benefits

Be sure to tell the patients all of the good things about the research, and what you perceive to be benefits of participating in a study like this.

Guidelines:

Mention two or three of the most important things – what do you consider to be the top three benefits?

List the benefits of participating in this study:

1.	1		
2.	1,000	 	1. t
3.		 	
1			· · · · · · · · · · · · · · · · · · ·
5.		 	

Recruiting for Studies

How to Give Advice and be Listened to: Counseling Guidelines

As a breast cancer survivor, you may know a lot about your cancer experience and treatment, but recruiting other patients and women to participate in research about the cause of cancer may require new skills for you. You may get into discussions with women that require some counseling skills. Here are a few tips on how to counsel effectively. Some of these suggestions you may already know. Others may be new to you.

Counseling/Recruiting Guidelines

- Be supportive and non-judgmental-nothing she says is bad or stupid.
- Ask open-ended questions that can't be answered with yes or no. Questions that begin with why, what, or how for example, will give fuller answers.
- Make sure the questions you ask are ones you can and would answer yourself. Don't ask questions that are too technical or too personal.
- If there is a disagreement, don't defend or argue. Ask more questions to broaden the perspectives. For example, why do you think that...? Are you worried/afraid that...?
- Because you are a survivor, she might want you to tell her what to do. Guide her, but make sure whatever decision is made is her own.
- Reflect back to her what she has said, especially if you are unsure about what she means or if she seems unsure of herself. For example, So you feel/think that....

Recruiter Role

How to Give Information and be Listened to: Research Study Discussion

The guidelines on the previous page help create a sense of trust and a positive tone in a discussion session. It is also important to direct the discussion is such a way that you know what kind of information is needed. Here are some guidelines for directing your discussion:

- Find out what concerns she already has
- Find out what she knows about research or epidemiological studies. Does she worry about being a "guinea pig"? Does she think it is risky? What does she know about others' experience?
- Find out how she feels about participating in research in general. Does she have any fears about the blood drawing, contamination of her blood, or the caffeine tablet?
- Use the DIB guidelines Decision, Involvement, and Benefits
- Encourage her to think about the issues and talk with you and the study staff about them.
- Leave her with information and a phone number to call. Tell her you'll check back with her in a week or so (if appropriate) and encourage her to call about questions.

Talk about the different kinds of questions suggested here. A good recruiting session will:

- > get the facts
- > discuss feelings and give emotional support
- > give facts/informational assistance
- > help solve problems
- > guide a decision

Recruiting Techniques Exercise

Working in groups of three or four, fill in the spaces provided with one or two additional questions that will help you reach the counseling goal listed to the left.

<u>Goal</u>	Questions or Statement
1. Get the facts	What do you understand about this study?
2. Discuss feeling and give emotional support	How do you feel about participation in this kind of research?
3. Give facts/informational assistance	I am a survivor. We are all interested in knowing more about what causes cancer. This study can help us understand why some of us have cancer and other women don't.
4. Help solve problems	Are you unable to take caffeine or do you have enough time to participate?
5. Guide a decision	Do you have questions I can answer?

How Will You Do It?

Scripts/Role play Contact Sheet

Sequence of Actions
Interview Topic Outline
Questions for those who refuse to participate

Date	mailed	to	recruiter

Date to notify UAMS staff & return contact sheet

Date recruiter mailed contact sheet to UAMS

UAMS BREAST CANCER RESEARCH CASE CONTACT SHEET

SUBJEC	CT'S NAMI	E:						
SUBJEC	CT'S I. D. N	UMBER:			PHON	E NUMBE	R:	
SUBJEC	CT'S ADDR	RESS:						
SUBJEC	CT'S RACE	:			A	\GE:		
RECRU	ITER'S NA	ME:						
		NAME:						
				ATTE	<u>MPTS</u>			
				Partio	cipation		Meeting Place	ce
Date	Time	Comments		Yes	No	Home	Clinic	Hospital
						·		
	· -	ck the followin that the subject	-		-	•		
☐ Enthus	iastic	□ Nervous	□ N	ot sure if th	ey want to p	oarticipate		
☐ Excited	l	☐ Hesitant				ation about 1	the study	
□ Willing	-	☐ Angry	$\square Q$	uestions for	r study staff			
☐ Pleasar	it l Comments:							

Please attempt to c	call subjects at least once betw	veen 9-11 a.m.; 1-5 p.m	.; and 7-8 p.m. before deter	mining
-	them. Please attempt to cont		-	
return date				

VOLUNTEER RECRUITMENT FORM

[FORM FOR CASES, WOMEN WITH BREAST CANCER]

Hello, may I speak with	(WOMEN'S NAME)	
(ONCE WOMAN IS ON TH	E PHONE):	
received a letter fromimportant study at the Univers	I'm a breast cancer survivor from a while ago and a pink postcard from nity of Arkansas for Medical Sciences and Jeffers doctor there gave the study director your name.	ne, telling you about an son Regional Medical
would like to tell you about the ASK FOR A BETTER TIME	TO CALL BACK. TIME:	
Doctors and researchers are co	ncerned because breast cancer is becoming mor	e common in (African-

Doctors and researchers are concerned, because breast cancer is becoming more common in (African-American) women, and not much is known about what causes it or how to prevent it. Doctors at the Cancer Center are running a study to try to learn some of the causes of breast cancer (especially in African-American women). This study will compare women who have had breast cancer to women who have not, to learn why some get cancer and others do not.

I want to tell you right at the start that there will be no cost to you. In fact, you will receive \$25 as our way of thanking you for participating in our study. I also want you to know that your privacy will always be protected. Only myself, the interviewer, and the study director will be aware of your name. From the time of the interview, only an identification number that has been assigned to you will be used, not your name. Also, this is not a treatment study and your involvement will not interfere with any treatment you may be undergoing.

A female researcher from the Cancer Center will meet you at a place where you feel comfortable, to interview you (ex: your home, clinic, or at a doctors appointment). At the interview, you will be asked questions about your diet, health history, and other lifestyle habits. There will be no embarrassing questions.

Before the interviewer comes, you will be asked to take a small caffeine tablet -- which is in coffee--a simple NoDoz tablet.

IF THE WOMAN HAS PROBLEMS WITH CAFFEINE: We would still like you to be in the study, but not take the caffeine tablet or give the urine sample. When you meet with the researcher she will interview you and take a small blood sample.

Otherwise: You will be asked to provide a urine sample five hours after taking the NoDoz tablet, which can be taken at home, or the hospital or clinic. You'll get complete instructions about this from the interviewer, who will also take a small blood sample when she sees you.

(CONTINUE DESCRIBING STUDY):

You will be mailed the consent form and instructions for the caffeine tablet and urine sample that the interviewer will have talked to you about. Then you can meet with the researcher so she can complete the interview and collect the specimen(s). This will probably take about one hour. That's all there is to it.

So.	do vo	u have	anv o	questions?
\sim \sim \sim				

by to you have any questions.
(IF THEY HAVE QUESTIONS THAT YOU DO NOT KNOW THE ANSWER TO, TELL THAT AN INTERVIEWER WILL CALL THEM CALL BACK TO ANSWER ANY QUESTIONS).
Do you think you would be able to participate in this study? () YES
(IF NO , TRY TO FIND OUT WHY NOT, AND TRY TO CHANGE THEIR MIND. IF THEY STILL SAY NO , ASK):
May I ask you just a few short questions on the phone? (SEE QUESTIONS FOR NON-PARTICIPANTS ON THE LAST PAGE)
(IF THEY AGREE TO PARTICIPATE, SAY):

I will tell one of our interviewers that you are interested in being in the study, and she call you to set up an interview appointment date.

Is this the best phone number for them to reach you?

OR, IF THERE IS A BETTER NUMBER, WRITE IT DOWN HERE).	
()	
Is there a good time of day to call you? TIME:	

TE VEC WRITE DOWN THE BHONE NUMBER THAT VOIL CALLED

Thank you so much for your time, and for agreeing to be in this study. One of the researchers will be calling you soon.

QUESTIONS FOR THOSE WHO REFUSE TO PARTICIPATE (Circle responses)

1. Do you currently smoke cigarettes?			Yes	No	
If no: Did you	ı ever smoke regu	ılarly?	Yes	No	
2. Do you ha	ve any children, a 1 2	and if so, how n		ve?	more than 4
3. On a norm 0 1	nal day, how many 2	servings of ve	getables would 4	you say you 5	a eat? more than 5
4. On a nor and pork.	mal day, how mar	ny servings of n	neat would you	say you eat	? This includes poultry, beef
0 1	2	3	4	5	more than 5
5. In a usual 0 1	week, how many	times do you d	rink any alcoho 4	l, that is, wi 5	ne, beer or liquor? more than 5
6. What was	the highest grade	or year of scho	ol that you com	pleted?	
7 What is vo	our race?				

- 7. What is your race?
 - 1. African-American (black)
 - 2. Caucasian (white)
 - 3. Hispanic/Latino
 - 4. Asian or Pacific Islander
 - 5. American Indian or Alaskan Native

Date	mailed	to	recruiter

Date recruiter mailed contact sheet to UAMS

UAMS BREAST CANCER RESEARCH CONTROL CONTACT SHEET

SUBJEC	CT'S NAM	E:						
SUBJEC	CT'S I. D. I	NUMBER:			PHON	E NUMBE	ER:	
SUBJEC	CT'S ADD	RESS:						
SUBJEC	CT'S RAC	E:			AGE:			
RECRU	ITER'S N	AME:	··-					
INTERV	/IEWER'S	S NAME:			Service and Advisory Constraints			
				ATT	EMPTS			
				Pa	articipation		Meeting	g Place
Date	Time	Comments		Yes	No	Home	Clinic	Hospital
								write down any vith the subject.
☐ Enthus	iastic	□ Nervous	\square N	ot sure i	f they want to	participate		
□ Excited		☐ Hesitant			ke more inform			
□ Willing		□ Angry	$\Box \mathbf{Q}$	uestions	for study staf	f		
☐ Pleasar Additiona	ıt l Comments:	:						

VOLUNTEER RECRUITMENT FORM

[FORM FOR CONTROLS, WOMEN WITHOUT BREAST CANCER]

Hello, may I speak with						
(WOMAN'S NAME)						
(ONCE WOMAN IS ON THE	PHONE):					
Hello, my name is	. I'm a breast cancer survivor from					
	received a letter from the Driver's License Bureau or Social Security					
Division a while ago and a pink	ostcard from me, telling you about an important study at the					
University of Arkansas for Medi	al Sciences and Jefferson Regional Medical Center on breast cancer.					
If you have time, I would like to	ell you about the study. If no . If yes .					
ASK FOR A BETTER TIME TO	CALL BACK. TIME:					
	erned, because breast cancer is becoming more common in (African-					

Doctors and researchers are concerned, because breast cancer is becoming more common in (African-American) women, and not much is known about what causes it or how to prevent it. Scientists at the Cancer Center are running a study to try to learn some of the causes of breast cancer (especially in African-American women). This study will compare women who have had breast cancer to women who have not, to learn why some get cancer and others do not.

I want to tell you right at the start that there is no cost to you. In fact, you will receive \$25 as our way of thanking you for participating in our study. And I want you to know that your privacy is always protected. Only myself, the interviewer, and the study director will be aware of your name. From the time of the interview, only an identification number that has been assigned to you will be used, not your name.

A female researcher from the Cancer Center will meet you at a place where you feel comfortable, to interview you (ex: your home). At the interview, you will be asked questions about your diet, health history, and other lifestyle habits. There will be no embarrassing questions.

Before the interviewer comes, you will be asked to take a small caffeine tablet --which is in coffee--a simple NoDoz tablet.

IF THE WOMAN HAS PROBLEMS WITH CAFFEINE: We would still like you to be in the study, but not take the caffeine tablet or give the urine sample. When you meet with the researcher, she will interview you and take a small blood sample.

Otherwise: You will be asked to provide a urine sample five hours after taking the No Doz tablet, which you can take at home. You'll get complete instructions about this from the interviewer, who will also take a small blood sample when she sees you.

CONTINUE	DESCRIBING	STUDY):
CONTRICE	DESCIONATION	

You will be mailed the consent form and the instructions for the caffeine tablet and urine sample that the interview will have talked to you about. Then you can meet with the researcher so she can complete the interview and collect the specimen(s). This will probably take about one hour. That's all there is to it.

So, do you have any questions?

(IF THEY HAVE QUESTIONS THAT YOU DO NOT KNOW THE ANSWER TO, TELL THEM
THAT AN INTERVIEWER WILL CALL THEM BACK TO ANSWER ANY QUESTIONS).

Do you think you would be able to participate in this study? () YES
(IF NO , TRY TO FIND OUT WHY NOT, AND TRY TO CHANGE THEIR MIND. IF THEY STILL SAY NO , ASK):
May I ask you just a few short questions on the phone? (SEE QUESTIONS FOR NON-PARTICIPANTS ON LAST PAGE)
(IF THEY AGREE TO PARTICIPATE, SAY):
I will tell one of our interviewers that you are interested in being in the study, and she will call you to set up an interview appointment date.
Is this the best phone number for them to reach you?
(IF YES , WRITE DOWN THE PHONE NUMBER THAT YOU CALLED. OR, IF THERE IS A BETTER NUMBER, WRITE IT DOWN HERE).
Is there a good time of day to call you? TIME:
Thank you so much for your time, and for agreeing to be in this study. One of the researchers will be calling you soon.

QUESTIONS FOR THOSE WHO REFUSE TO PARTICIPATE (Circle responses)

1.	Do you cur	rently smoke	cigarettes?	Y	es	No	
If n	o: Did you	ever smoke	egularly?	Y	es	No	
2. No	•	ve any childre 1	n, and if so, h	now many do	you have? 4		more than 4
3.	On a norma	al day, how n	nany servings	of vegetables	would you	say you	eat?
0	1	2	3	4		5	more than 5
4. and 0	On a norm l pork. 1	nal day, how 2	many serving	s of meat wo	uld you say	you eat?	? This includes poultry, beef more than 5
5.	In a usual v	week, how ma	any times do	you drink any	alcohol, th	at is, wi	ne, beer or liquor?
0	1	2	3	4		5	more than 5
6.	What was t	the highest gr	ade or year of	f school that y	ou complet	ed?	
7.	What is yo	ur race? ican-America	ın (black)				

- 2. Caucasian (white)
- 3. Hispanic/Latino
- 4. Asian or Pacific Islander
- 5. American Indian or Alaskan Native

Sequence of Subject Recruitment To Breast Cancer Study

- 1. Cases are identified through UAMS, VAMC or JRMC Tumor Registries. Controls are identified by Arkansas Driver's Services or Social Security lists.
- 2. A letter will be sent from the patient's doctor by UAMS staff or from Driver's Services or Social Security, telling him about the study.
- 3. Cases are assigned to recruiters. Packets are sent to recruiters and include:
 - Contact sheet
 - Script for phone call
 - Reimbursement forms
 - Self-addressed stamped envelopes from UAMS
- 4. Post-cards will be sent by UAMS staff to the subject with the recruiter's picture and name.
- 5. Recruiter will contact subjects within 21 days if possible.*
- 6. Recruiters return the information (completed contact sheet) back to UAMS.
- * At any time, recruiters may call UAMS staff or assistance with subject phone numbers that may be incorrect.

INTERVIEW TOPIC OUTLINE

- DEMOGRAPHICS: Very brief personal, demographic information.
- SMOKING HISTORY: Few questions on cigarette smoking for 6 months or longer.
- OCCUPATIONAL HISTORY/EXPOSURE: Brief information on five (5) longest held jobs and related environmental exposure.
- DIET: Meat/Poultry/Fish eaten over year prior to diagnosis/past year including frequencies and cooking methods.
- MEDICAL HISTORY: A few questions on specific diseases; and medications currently taken.
- FAMILY HISTORY: Cancer history of all immediate blood relatives: parents, siblings, children.
- REPRODUCTIVE HISTORY: Childbirth; breastfeeding practices for each child.
- PHYSICAL ACTIVITY: Average amount of exercise over year prior to diagnosis/past year.
- LIFESTYLE: A few very brief, confidential questions on household income and social security number.

TOTAL INTERVIEW TIME: 50-90 MINUTES

Resources

Expense Report Form

Sample Recruiter Card

Post-training Evaluation

Recruiter Memo

APPLICATION FORM

NAME:	
ADDRESS:	
HOME #:	
HOME #:	
WORK #:	·
S.S.#:	
	Your social security number is need by the University System, so that you will get reimbursed for your efforts.
Signature:	

UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES RESEARCH EXPENSE/EVENT REPORT FORM #2 EPI STUDY RECRUITER

Your Complete Name (Please Print)			Your Signature							
; :		ete Mailing A								
Your	Social	Security Num	iber							
Date	ID#	Will Participat e	Will Not Participant	In Home Hospita	Interviewed Staff Only					
			-							
		•	V IS TO BE C							
# of co	ntacts v	vho will not p	articipate S5	per Persoi	n Contacte	=	Total			
of co	ntacts v	vho will partic	cipate xx) per Pers	on Particip	eating =	Total			
Гotal R		rsement =								

UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES EXSPENSE/EVENT REPORT FORM EPI STUDY RECRUITER FORM #1

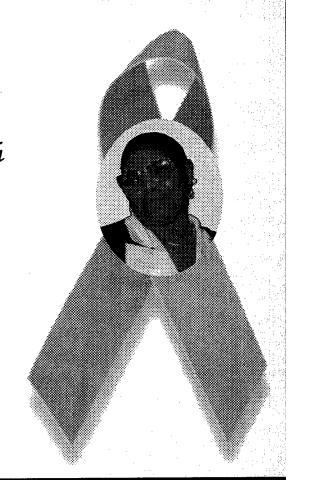
Name			Signature	
Complete	Mailing Address			
Social Sec	urity Number	· (Car Tag/License P	late # For Driver Onl
DATE	TRAINING FEE	CITY	COUNTY	ROUND TRIP MILEAGE
Γraining Fe	ee = \$35.00 ;		=	Total

Нi,

My name is Lillie Watson.

I am a breast cancer survivor and do patient education and outreach at the University of Arkansas for Medical Sciences.

Your doctor sent you a letter about a breast cancer study. I am going to call you soon to talk to you about it.



Arkansas Cancer Research Center, Slot 725
University of Arkansas for Medical Sciences
4301 W Markham St
Little Rock AR 72205-9985

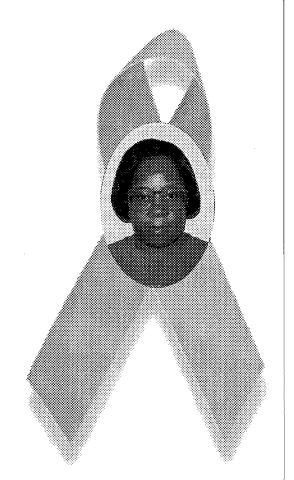
Address Correction Requested

Hi,

I am a breast cancer survivor and do patient education and outreach at the University of Arkansas for Medical Sciences.

Your name was randomly picked from the Driver's License Bureau and I am going to call you soon to tell you about a study we are conducting at UAMS.

My name is Christine Oliver.



Arkansas Cancer Research Center, Slot 725 University of Arkansas for Medical Sciences 4301 W Markham St Little Rock AR 72205-9985 Address Correction Requested

EPIDEMIOLOGICAL PROJECT STAFF LISTING

NAME	NUMBER	
Christine B. Ambrosone, Ph.D.	Research Epidemologist	(501) 686-8574 X 153
Carol Sweeney, Ph.D.	Research Epidemologist	(501) 686-8574 X 159
[*] Rebecca Morris-Chatta, MPH	Projects Director	(501) 686-8574 X 156
Deborah O. Erwin, Ph.D.	Associate Director for Education	(501) 686-8801
Ștephanie Long, BS	Project Director	(501) 686-8574 X 150
Manal Fares, MPH	Research Assistant	(501) 686-8574 X 158
Rachel Butler-Green, BS	Research Interviewer	(501) 686-8574 X 151
Kristy Bondurant, BA	Research Interviewer	(501) 686-8574 X 152
Cecilia Twillie-Woods, BS	Research Interviewer	(501) 686-8574 X 154
Sean Walls, BA	Research Interviewer	(501) 686-8574 X 155
Shelley Sontag, BA	Research Interviewer	(501) 686-8574 X 157

Breast Cancer Study Recruiter Training

Program Evaluation

Please take a minute to answer these questions about today's sessions. Your information will be used to plan future sessions.

1. Tell us how strongly you agree or disagree with the following statements by circling the number for the appropriate answer.	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
(a) I understand the barriers and benefits which influence a person's decision to participate in research.	1	2	3	4	5
(b) I feel more comfortable about talking with other patients and people about participating in research.	1	2	3	4	5
(c) I feel more confident in advising women who are considering being part of this research.	1	2	3	4	5
(d) I know how to use available resources and materials, like the study description and interview topic outline.	1	2	3	4	5
(e) I understand how to contact patients and controls.	1	2	3	4	5
(f) I understand how to use the contact forms.	1	2	3	4	5
(g) I understand the process of the research project and how patients are selected and enrolled better than I did before.	1	2	3	4	5
(h) I am ready to begin contacting new patients and controls.	1	2	3	4	5
(i) an general, the training materials in the manual were easy to use and understand, and appropriate for the topics.	1	2	3	4	5
(j) In general, the exercises and role playing were helpful to me.	1	2	3	4	5
(k) I had enough time to ask questions and interact with others to understand the material presented.	1	2	3	4	5

2. To assist us in planning future training sessions, we need your comments, criticisms, and suggestions on this program. With 5 being the *highest rating* and 1 being the *lowest rating*, tell us how *informative* and *useful* the information presented today has been for you. Please circle 1, 2, 3, 4, or 5 for each category below.

	How Informative			rma	ative	How useful	How useful is the information					
Epidemiological Research	1	2	3	4	5	1 2	3	4	5			
Presentation of Program description and goals	1	_2	3	4	5_	1 2	3	4	5			
Mechanics of Recruitment	1	2	3	4	5	1 2	3	4	5			
Barriers and benefits to participation	1	2	3	4	5	1 2	3	4	5			
Script for recruiting	1	2	3	4	5	1 2	3	4	5			
Role-playing Exercises	1	2	3	4	5	1 2	3	4	5			
Evaluation Techniques/Contact Forms	1	2	3	4	5	1 2	3	4	5			
Final Discussion, Questions, Evaluation	1	2	3	4	5	1 2	3	4	5			

3. Rate your satisfaction with the training session by circling the appropriate score on the scale below.

	Very Unsatisfied	Unsatisfied	Neutral	Satisfied	Very Satisfied
(A) Location	1	2	3	4	5
(B) Facilities	1	2	3	4	5
(C) Training Format	1	2	3	4	5
(D) Speakers	1	2	3	4	5
(E) Length of time	1	2	3	4	5
(F) Printed Materials	1	2	3	4	5
(G) Luncheon	1	2	3	4	5

4. Finally, please answer the following questions:

A.	The best (most helpful) part of the training session for me was:
В.	The least helpful part of the session for me was:
C.	Please give suggestions which help us improve the training program for the next group:

MEMO

To: Breast Cancer Study Interviewers and Recruiters

From: S. Long

Date: October 11, 1998

Re: Revision because of phone number changes

The buddy system is a strategy to improve communication between interviewers and recruiters throughout the recruitment phase. Initially, interviewers will contact recruiters the day, they mail out recruitment packets. Interviewers will tell the recruiters how many potential subjects they are mailing to the recruiter as well as how many are priority. Neon labels will be attached to those cases who must be contacted immediately (within 48 hrs). If a recruiter cannot reach a priority case within this amount of time, they need to contact their interviewer buddy, to let them know. This way, the interviewer can assist the recruiter. It is imperative that we do not lose any potential subjects, due to the late diagnosis date. Whether or not there are new subjects packets to send, interviewers will contact their recruiter buddies once per week, to see how they are, to ask about recruitment progress, and to see if they have any questions or problems.

Recruiters now have 21 days from the "mail date" to contact their potential subjects. After 21 days, recruiters should return the information in the postage paid envelope provided to:

Stephanie Long Surgical Oncology Research UAMS Slot #725 4301 W. Markham St. Little Rock, AR 72205 (501) 686-8574 Ext. 150 Rebecca Morris-Chatta Surgical Oncology Research UAMS Slot #725 4301 W. Markham St. Little Rock, AR 72205 (501) 686-8574 Ext. 156

Recruiters and their Interviewer buddies.

RECRUITER	INTERVIEWER	NUMBERS
Joanne Helgeson	Terri Teague	(501) 686-8574 x 152 Pager 688-2256
Linda Creggett	Cecilia Woods Pager 395-8233	(501) 686-8574 x 154
Gwendolyn Hill	Rachel Butler-Green	(501) 686-8574 x 151 Pager 395-8247
Laurita Irvin	Shelley Sontag	(501) 686-8574 x 157

^{*}If you have any questions please contact Stephanie Long or Rebecca Morris-Chatta at the following toll free number 1-877-888-0351.